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Critical care diaries: an exploration of patient perceptions using Glaserian Grounded Theory

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Abstract

Background

Recognition of the psychological needs of critical care patients has been an area of increasing interest in recent years. Use of critical care diaries written on behalf of critically ill patients is one intervention that has been adopted in the study site in South Wales. Little is known about the benefits, limitations or potential for harm of such diaries and fundamentally there is a lack of representation of patients' views in diary use and development. The aim of this longitudinal qualitative study was to provide an in-depth insight into critical care survivor experiences and use (or not) of a critical care diary during the first 12 months of their recovery to inform development of a theory and future diary use.

Method

Glaserian Grounded Theory (GGT) was the selected methodology for this particular study. It was important that patients' perceptions and experiences were captured and that a theory about diary use could emerge. Serial qualitative interviews (SQI's) were used at 2, 6 and 12 months post- ICU discharge. The longitudinal process was fundamental in capturing participants' experiences, views and interaction with their diary, or not, during the first year of their recovery.

Key findings

The substantive theory is that humans seek coherence about what happened during their critical illness. Part of the process encompasses patients being ready to know what happened. Those patients who feel ready to know need to replace the disruption or rift that has occurred in the normally intact timeline of their lives. In order to do this, patients draw on relevant information available to them. Having a critical care diary can be instrumental in helping patients resolve the uncertainty, anxiety and stress that negatively impacts on their health and recovery. However it can also fail to allay concerns and thus increase anxiety and rumination where questions are left unanswered; acting as a potential hindrance to recovery.

Conclusions

The original contribution to knowledge is in the provision of a longitudinal qualitative study that provides in-depth insight into critical care survivors' experiences of critical illness, recovery and use, or not, of their diary during this process. Restoring a sense of coherence to disrupted life and identity is important in the aftermath of critical illness and diaries. Diaries may act to help or hinder the recovery process and therefore appropriate supportive mechanisms need to be in place. A diary is one of many means of supporting patients, but should not be used in isolation.

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Chapter 1

1.0 Introduction

The need to address the psychological needs of critical care survivors has become an area of growing interest in the United Kingdom (UK) in the past decade. Patient experiences and memories of critical care can impact on individuals' lives after discharge from hospital (Myhren *et al.*, 2010, Misak, 2011). According to Ewens *et al*. (2013) some patients remember and retain strong emotions and anxiety related to their experience. The psychological implications for patients admitted to critical care has become a topic of interest in the last decade with studies linking memory disruption or delusional thoughts to physical and psychological symptoms manifesting in survivors of critical care (Deacon, 2012, Elliot & Rattray, 2012). This has led some critical care units to introduce patient diaries as a memory aid for patients to read after the critical illness event and discharge home in an effort to help patients make sense of what is often a period of time they do not remember (Jones *et al.,* 2010, Egerod *et al*., 2011a, Egerod *et al*., 2011b).

It is estimated that around 9,000 patients per year are admitted to one of the 16 existing critical care units in Wales at a cost of around £1932 per night. Advances in healthcare mean that approximately 75% patients will survive and are discharged home to recover (Welsh Government, 2013). In 2006 '*Designed for Life: Quality Requirements for Adult Critical Care in Wales'* identified the need for a psychologist role in critical care to assess, identify and provide advice for those patients at risk of

psychological problems (Welsh Assembly Government, 2006). However investment in provision of Clinical Psychologist roles in critical care in Wales and the UK remain limited with only eleven currently in post (Highfield, 2016).

In 2009 the National Institute for Health and Clinical Excellence (NICE) '*Clinical Guideline 83: Rehabilitation after critical illness'* recommended development of services to meet the rehabilitation needs of critical care survivors. Years later and the rehabilitation needs of critical care survivors remains an area requiring development, not only in Wales, but nationally. There has been an increase in research published on physical aspects of rehabilitation with a focus on early mobility and exercise during patients' stay in critical care (Koch *et al.,* 2011, Adler, 2012, Parker & Needham, 2013). However, the psychological ramifications related to surviving admission to critical care still seem to be of secondary importance to the issue of physical debility (Jones *et al.,* 2010, Rattray, 2013). In 2013 the Welsh Government published '*Together for Health-A Delivery Plan for the Critically Ill: A Delivery Plan up to 2016 for NHS'*. This document does not identify rehabilitation and recovery of critical care survivors in the key issues outlined within it, but it does advocate for further research. '*A Strategic Vision for Critical Care Services in Wales'* (2013) which was produced by the Critical Care Networks notes the need to include patients and carers in shaping the experience of critical care.

Essentially critical care priorities centre on provision of enough beds in Wales to facilitate effective care and management of critically ill patients during the immediacy of their life threatening event. The psychological needs of critical care survivors have

been acknowledged, but investment in provision of support in the aftermath of patients' critical illness remains to be seen. It is not surprising that some critical care units have adopted critical care diaries as one mechanism that could possibly be beneficial to patients who struggle to understand what they have been through. A concern has to be that there is a lack of research supporting patient diary use and what patients think of them.

This thesis focuses on a longitudinal qualitative in-depth exploration of patients' experiences of critical illness and the role (or not) that their diary has played during the following twelve months of their recovery. This in-depth insight from the patient perspective will be used to provide recommendations and inform future diary use.

1.1 Study intent

The initial literature review is outlined in Chapter 2: it identifies that, despite the growing interest in use of patient diaries in critical care, there is a lack of patient focused research. This means that diaries are currently being adopted without patient feedback on how they feel or what they want from their diary. The evidence base to support diary use in critical care remains contentious, with existing research yet to substantiate their usefulness for patients (Ullman *et al.*, 2014).

The research approach selected for this study is Glaserian Grounded Theory (GGT) and is appropriate to use where little is currently known (Holton & Walsh, 2016). It was important that patient's perceptions and experiences were captured and that a

theory about diary use could emerge. Serial qualitative interviews (SQIs) were used at two, six and twelve month's post- ICU discharge. The longitudinal approach was fundamental in capturing participants' experiences, views and interaction with their diary during the first year of recovery.

In GGT the research does not usually start with a research question as this emerges from participant data. However, for the purposes of the research proposal, grant application and transfer report, the following research questions that capture the gaps in the existing evidence base were used:

- What are patients' experiences following critical illness?
- What role, if any, do diaries play in their recovery?
- What insight does this provide for future critical care diary use?

The aim of this study is to provide an in-depth insight into critical care survivor experiences and use (or not) of a critical care diary during the first twelve months of their recovery to inform development of theory and future diary use. Therefore the following objectives were identified:

To critically explore participants':

1. Experiences of critical illness and their ensuing recovery during the first 12 months.

2. Use of their critical care diary (or not) including if, when, and how they used it and to elicit how diaries may be useful at different time points during their recovery and rehabilitation.
3. Perceptions of diary content (type, breadth and depth), impact of this and role, if any, they felt their diary had for them during their recovery.
4. Environmental and demographic factors that may impact on perceptions of the diary

Clearly with a set period of time for starting and completing the PhD process it was important to identify gaps in the current evidence base. The most obvious research gap was that the patient voice was minimal or missing from the existing evidence. Pivotally, research is required to establish patient perceptions of having a critical care diary kept on their behalf which they can read post-discharge from hospital, during their recovery. It is vital to hear what patients have to say about their diary and their experiences, to empower them in a process of which they currently have no part.

1.2 Context of critical care and diary use

Patients may require admission to critical care for a plethora of reasons including pneumonia, trauma, myocardial infarction, sepsis and Guillain Barré Syndrome (Adamson *et al.*, 2004, Löf *et al.,* 2008, Toien *et al*., 2010). Survivors of critical care are known to exhibit physical and psychological problems (Adamson *et al.,* 2004, Knowles & Tarrier, 2009, Jones *et al*., 2010, Bäckman *et al.*, 2010). Comparisons between studies are fraught with the problem that researchers have used different

approaches, timeframes, case mix and tools to assess psychological impact of illness.

Critical care units, also known as intensive therapy units (ITUs), intensive care units (ICUs) and high dependency units (HDUs), aim to meet the needs of patients who require closer observation and support than can be provided in ward environments. Admission to critical care is deemed a crisis for both the patient and the relatives; it can be likened to a traumatic event (Stayt, 2007).

Critical care environments contain various forms of technical devices used to support the physiological needs of the critically ill, such as ventilators for respiratory support and infusion devices to deliver medications and fluids in a controlled manner (Almerud *et al.*, 2007, Meriläinen *et al.*, 2010). The critical care unit tends to be busy twenty four hours a day and consequently this can impact on the patient experience because of disruption to normal night and day routines (Tamburri *et al.,* 2004). It has been identified that short term exposure to noise can cause surges in adrenaline secretion with subsequent vasoconstriction and high blood pressure, altered heart rate and increased respiratory rate, which in turn disrupt the quality of sleep (Hweidi, 2007, Meriläinen *et al.*, 2010). These issues can lead to psychological problems during recovery in patients who have been ventilated and sedated. Patients potentially have a gap in memory or recall of events that have occurred while they have been critically ill or a distorted perception of the reality of what has happened (Almerud *et al.*, 2007, Storli, 2009). It has been postulated that critical care patients have a desire to know what is happening and what has happened to them thus

providing constant reorientation of past and present (Hupcey & Zimmerman, 2000, Bäckman & Walther, 2001, Egerod & Bagger, 2010). However this may not be true of every individual with some patients preferring not to dwell on what they have been through (Litz, 2008).

Diaries were implemented in 2009 as part of care delivery in the South Wales critical care unit that forms the study site for this research: the first known use of patient diaries in Wales. The diary is written on behalf of the sedated and ventilated patient in critical care by nurses, other healthcare professionals (HCPs) and relatives. It is thought that the diary can potentially form a bridge between a patient's sense of incomprehension of their critical illness journey and the reality of what has happened.

The diary is commenced for patients who are critically ill and require ventilation for two days or longer as the literature suggests these patients are most at risk of amnesia (Jones *et al.,* 2010). It has been claimed that a diary can used to try to fill in memory gaps and some researchers have considered this as being beneficial in helping the patient to be realistic about their recovery process (Bäckman & Walther, 2001, Egerod & Christensen, 2010). It is believed by some that the diary can provide patients with insight into the path their illness journey took while they were unconscious (Bäckman & Walther, 2001, Combe, 2005). The potential harmful effects of diary use have not been explored in the literature (Ullman *et al.,* 2015).

1.3 Significance of the study

Critical care diary use is on the increase because it provides one way of supporting patients and their families psychologically during a traumatic period in their lives (Egerod *et al.,* 2011a). Psychological needs of patients remain a secondary consideration in the current clinical setup of critical care where managing life threatening events has to be the priority. Therefore critical care diaries written on behalf of patients for them to read during their recovery seem a simple idea. A fundamental concern is that the evidence base to support use of patient diaries is sparse. Particularly troubling is the lack of patient centred research about an intervention that is meant for their use. It is yet to be established what patients think of their diary, if, how, or when they may use it, if at all. This study provides the first known UK longitudinal qualitative study and in-depth insight into these concerns in the context of participants' critical illness, recovery and potential diary use as highlighted in the study aim and objectives.

1.4 Justification for the study

There is a paucity of research exploring diary use and representation of patients' views is currently lacking. Diary use seems to be motivated by and tailored to meet nurse's perceptions of what patients may value from a diary. The idea behind introducing critical care diaries is to help patients and this makes them an attractive proposition for HCPs who try to achieve this on a daily basis. Unfortunately this has led to a variety of approaches to diary format, and processes that are subjective. There is potentially a lot that can be done well or badly in terms of constructing and

handing over a diary to a patient (Jones, 2009a). Implementing a critical care diary cannot be a quick fix approach. It has complexities that nurses and other HCPs need to understand and consider prior to participating in the diary writing process. Gaining insight into participants' perceptions of their diaries enables their voice to impact on its evolution in clinical practice in the UK and beyond. There appears to be an assumption from current research on diaries that they are purely beneficial to patients, but without asking patients this remains unclear.

1.5 Reflexivity

Using reflexivity on their research is a way in which the researcher can overcome predetermined ideas of what Glaser meant by *"remaining open to what is actually happening"* (Glaser, 1978, p.3). The final hurdle for many grounded theory researchers is that they must have the ability to be aware of their own personal bias throughout the research process through reflexivity.

My career was based in critical care nursing, both in England and Wales and I had no experience or prior knowledge of diary use in critical care until my involvement in this study. I ran a module on psychological consequences of critical illness and developed an interest in the impact of critical illness on patient, families and HCPs.

Personal bias throughout the research was a risk because of my background as a critical care nurse. However, the current study involved something of which I had no prior knowledge. While patient diary use was new to me, I had depth of insight into the critical care aspect of care and management. At times prior knowledge of critical care did act as a barrier in thought processes. Although I knew there were psychological implications for patients following critical care admission, I had no idea of the realities that patients and family faced in the community, during their recovery. This meant I found it all interesting and experiences at times overshadowed perceptions of diaries.

I joined the Grounded Theory Institute online at the outset of the PhD as I recognised that support via blogs and the quarterly journal articles could be beneficial. I kept a grid of the terminology so that I could keep referring back to it when I felt confused and this was helpful. I attended a Grounded Theory Masterclass early on in the study to help me focus more clearly on the requirements of the methodology. I met with the diary team to establish a relationship and to discuss the study and work out a plan to take things forward.

The initial literature review in the next chapter was intentionally limited as Glaser points out that literature can increase preconceptions and biases prior to data collection, which can undermine the emergence of theory based on participant data as opposed to the literature.

1.6 Outline of thesis chapters

Chapter 2 provides an intentionally limited initial overview of literature related to critical care diary use, this was required in order to provide context to inform development of the research study protocol and in gaining research grant approval. Chapter 3 focuses on the study methodology and methods. Findings are presented in Chapters 4 to 7, these chapters outline and explore the conceptual categories and associated codes that emerged and are used to inform the discovery of the substantive grounded theory. A grounded theory of needing coherence: repairing the rift in life story and self-identity after critical illness and establishing the role of a critical care diary is explored in Chapter 8. Chapter 9 provides study conclusions, recommendations and outlines the original contribution to knowledge.

Chapter 2: Initial literature review: patient diaries in critical care

2.0 Overview of the chapter

This chapter forms an intentionally limited initial literature review on patient diaries in critical care, it was used to provide knowledge and understanding of the current evidence base and inform development of the study protocol. The literature search strategy is outlined and rationale for diary use is explained. The literature review section sets the context of current research, types of diary, structure and diary writing. The role of the diary and existing theories about diaries are acknowledged.

The literature review conducted for the purposes of the research proposal and grant application identified a lack of research to support diary use and patients' views were not at the forefront of existing research.

2.1 Literature review in Glaserian grounded theory (GGT)

The current chapter is representative of an intentionally limited initial literature review regarding critical care diaries. It was conducted over the first year of the study to inform the research proposal and grant application. This is in keeping with the principles of GGT where Glaser emphasises against developing too broad an insight into the topic area, so as not to undermine the process of following data to identify relevant literature based on what patients say (Glaser, 2010). This is an important

aspect of maintaining theoretical sensitivity in GGT and the need to establish originality (Glaser, 1978; Glaser, 2012).

According to McGhee *et al.* (2007) the argument for conducting a literature review prior to developing a research proposal lies in providing justification for the research study to meet requirements for PhD proposals and research ethics committees. It also enables the researcher to avoid conceptual and methodological pitfalls. The literature review highlights the extent of current knowledge on the topic and can determine if grounded theory is an appropriate choice for the research. Acknowledging this, the researcher did find that a preliminary review of the current evidence base on patient diaries in critical care was useful in ensuring her study addressed a research gap. Prior to reading the existing evidence base she had been considering looking at critical care diaries and incidence of Post-traumatic Stress Disorder (PTSD). However, the literature indicated that the evidence base for this aspect was already growing, but fundamentally patient perceptions were lacking with little actually known about diary use, patient expectation and potential benefits or limitations.

Dunne (2011, p.111) states that Grounded Theory is an appropriate method for a topic where there is little ‘extant’ knowledge. According to Procter (1995) the crux of the process is how the data collection and raw data lead the way. As such, the researcher has been reliant on her ability to detach, refresh and conceptualise information based on the eventual interplay of data and constant comparative analysis.

Thornberg (2012) argues that a rigid stance on use of literature in GGT means that researchers would be unable to carry out studies in their own area of expertise. It is more realistic to accept that researchers should start their study admitting their theoretical understandings and preconceptions. Another criticism is that not doing a literature review at the outset in GGT is tantamount to laziness and a researcher could choose to use GGT for the wrong reasons (Suddaby, 2006).

Glaser (2010) has a less rigid stance than his original work suggested. He says the researcher can do a literature review at any time to meet demands for research proposals and grant applications. However, he states that if you have to do it, do it, but be open to it not being of any relevance. He points out that the literature is beside the point and that getting data is fundamental. The literature that the researcher ends up integrating consists of literature you would not have dreamt of including in the very beginning. It is at the writing up stage of the current study that the literature the researcher has used within the conceptual categories and theory demonstrates the diversity of literature that Glaser indicates is required.

2.2 Literature search methodology

The initial literature review was conducted in 2010-2011 to explore the use of diaries in critical care and aid in forming the study protocol. The literature review was conducted with no year restrictions using CINAHL, Medline, PubMed, PsycINFO and Google Scholar.

Inclusion criteria:

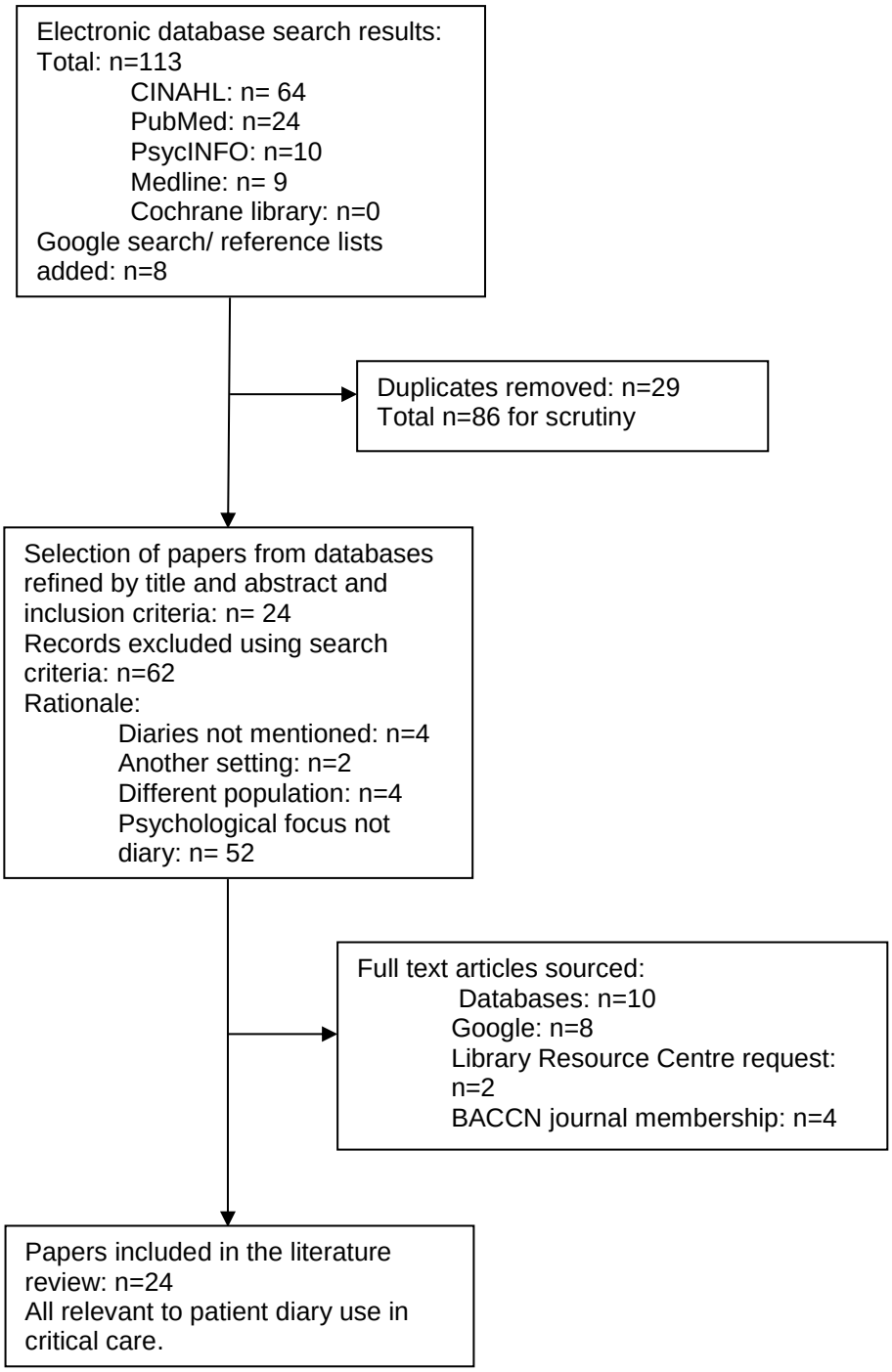
- Published Qualitative or quantitative research studies
- Published evaluations or descriptions of critical care diary use
- Adult critical care patients
- General critical care admissions
- Diary use
- English language

Exclusion criteria:

- Not focused on adult critical care patients
- Not about patient diaries in critical care
- Not translated into English language

Search terms used were diary, patient, critical care, intensive care, ITU, ICU, critical care survivors, psychological problems and coping. CINAHL provided 516 citations for diaries as a general term with Medline 4655 and PubMed 4802. The keywords used to refine the search were used singularly and in combination resulting in CINAHL citations of relevance as outlined in Figure 1 below. The citations were reviewed for duplicates and excluded via title or abstract. Individual citations that remained were scrutinized individually for relevance and Google Scholar citations identified a further 5 citations resulting in 24 critical care patient diary specific articles as detailed in Figure1 below:

Figure 1: the initial literature review on patient diaries



The review of the literature in a systematic manner resulted in twenty four full text articles that met the search criteria. These consisted of two pilot studies, two randomised and one non randomised control trial, three narrative analyses, two qualitative interview studies, four surveys and one comparative study, one focus

group, one qualitative questionnaire based study, five evaluations or descriptive articles, one dissertation and one description of a patient composed diary. These are identified in table 1 below:

Table1: Literature related to critical care diary use

Type	Author	Method	Notes	Limitations
4 surveys	Egerod *et a*l., 2007 (Denmark) Åkerman *et a*l., 2010 (Sweden) Gjengedal *et al.*, 2010 (Norway) Nydahl *et al.*, 2010 (German)	Telephone surveys	Allocation & structure of diaries	The surveys replicated each other. Culminating in Nydahl discovering no one in Germany knew about diaries. All studies noted on the left confirmed a lack of awareness of the purpose of keeping a diary and a lack of standardisation of diary processes- criteria, format and content and lack of guidelines.
1 comparative study	Egerod *et al.,* 2011b (Denmark, Norway & Sweden)	Comparative study based on above surveys data		Comparative overview of what is currently known about diary use in Scandinavia. Secondary analysis of qualitative data from telephone surveys.
2 RCTs	Knowles & Tarrier, 2009 (UK)	Pragmatic RCT, HADS anxiety & depression scores	Anxiety & depression	Knowles & Tarrier: timing of assessment process was time1- 1month, time 2- 7 weeks a longitudinal approach would have assisted in eliciting if there was change over time the Principle Investigator was not blinded and did the psychological assessment. Low numbers for RCT. Differences between control & intervention group.
	Jones *et a*l., 2010 (UK, Portugal, Italy, Denmark, Norway, Sweden)	Pragmatic RCT	New onset PTSD Both RCT studies predicted and reported reduced psychological symptoms by diary use in these studies.	Multiple methods of assessing psychological impact ICUMT at 1 month & 3 months post ICU discharge. PTS-14 when randomised & 3 months. Post-traumatic diagnostic scale & diagnostic interview at 3 months. Self-completed questionnaire from patients. Blinding of participants is a concern. Excessive assessment seems almost desperate to prove diaries work- adds bias as same authors pro diary stance potentially.
1 non randomised study	Bäckman *et al.*, 2010 (Sweden)	HRQoL-longitudinal study	Diary to improve recovery	Use of historical records and the disparities between the 2 groups studied in terms of age, size and severity of illness call into question the reliability and validity of the findings and the authors do note that a larger and randomised study is required.

3 narrative analysis	Roulin *et a*l., 2007 (Switzerland) Egerod & Christensen, 2009 (Denmark) Egerod & Christensen, 2010 (Denmark)		Diaries Diaries Diaries & charts	Descriptive overview of content analysis of diaries provided in all these studies and lack research focus. Gap is patient perspectives of the diary
2 interview based studies	Engström *et al.,* 2009 (Sweden) Egerod *et al.,* 2011a (Denmark)	Qualitative Interviews at 12 months Qualitative multicentre design-in-depth semi-structured Interviews at 6-12months Grounded Theory	Patients Patient & relatives	*n*=9 and interviewed 1 year post ICU. Interviews 15-40min-Did try to elicit patient views, but method needs improvement. *n*=19 patients, *n*=13 relatives. 6-12 months may provide different responses- a better selection of timeframe may have helped. 2 settings- general & thoracic surgical unit- don't really compare & not really multicentred. Convenience sample with interviews-individual & paired? Small sample size.
2 pilot studies	Bergbom *et al.,* 1999 (Sweden) Combe, 2005 (UK)	Questionnaire Structured Interviews 2, 6, 12 months (Panel used)	Patient & Relatives Retrospective then prospective diaries	*n*=10 patients & *n*=4 relatives- brief and needs development to represent patients views. *n*= 8 retrospective diary-too impersonal *n*=35 prospective diaries. 22 M & 13 F so gender imbalance. Panel made up of follow up team may negatively impact on honesty of participants.
1 focus group (subsidiary study to RCT)	Egerod & Bagger, 2010 (Denmark)	Focus group	Patient & diary	*n*=4 and female participant dominated the group. Gender difference 1 F & 3M. Poor representation of individuals experience of diary use as a result.
1 observational questionnaire	Bäckman & Walther, 2001 (Sweden)	Questionnaire 6 months	Patient & diary, structure. Debrief tool	*n*=41 with 100% response which is unusual- was there coercion? More research required to elicit patient views of diaries over time.
4 evaluation/ descriptions	Robson, 2008 (UK) Storli, 2009 (Norway) Jones, 2009a (UK) Hale *et al.,* 2010 (UK)	Questionnaire Described poster Described diary Described diary	Diary use	Robson-Evaluation using postal questionnaires. 36 sent and 20 returned. Some interesting aspects that need research Patient voice still missing in favour of nurses perceptions
1 patient composed diary	Rier, 2000 (Israel)	Notebook for communication formed diary	Patient voice	Sociologist first person account of their illness using notes he made while critically ill. Interesting, but not specific to the diary use being researched.

2.3 Background

Wider literature is not represented in this initial literature review chapter, but it is integrated in chapter 7 and 8. The purpose of this chapter was to establish an overview of existing literature at the outset of the current study just to inform development of the research proposal.

The writing of a diary on behalf of a patient was first described in Denmark in the 1980s when brief notes were made about key events that happened to patients, their environment and the world outside and were kept by nurses and relatives (Nortvedt, 1987). The rationale for this note keeping came from identification of the loss of time and memories experienced by patients following critical illness and was based on the 'dialogue in nursing' concept introduced in a Danish hospital in 1984. The project was designed to promote patient involvement in their care. However, the use of patient progress notes as an open source of information between staff and patient (open charting system) came under scrutiny from a legal viewpoint regarding confidentiality and the practice was ended as a result (Egerod *et al*., 2011b). Since then the use of critical care diaries as an adapted process (where official patient records are not part of the process) has spread throughout critical care units in Scandinavia.

In the 1990s Schou *et al*. (1993) in Norway, modified Nortvedt's (1987) idea and they began offering critically ill patients hand written notes. The principle behind patient diary development was to provide the story behind the patient's critical illness event;

it had been identified that patients often had difficulties remembering what had happened to them. The diary was considered to be a therapeutic intervention, which included provision of a diary (the story) and follow-up after discharge from hospital in order to put the story together (Schou *et al*., 1993). Diaries have evolved to include nurse led dialogue (Bäckman & Walther, 2001, Egerod *et al.*, 2007, Gjengedal *et al*., 2010) with the addition of photographs originating in Sweden (Bergbom *et al.,* 1999, Bäckman & Walther, 2001). The rationale for including photographs was that it was thought that photographs provided insight into how unwell the patient had been. This it was believed, enabled patients to be more realistic about their recovery and rehabilitation (Bäckman & Walther, 2001, Jones, 2009a).

Replicated telephone surveys in Denmark and Norway have demonstrated that 40% of the critical care units in their countries used a patient diary (Egerod *et al.,* 2007, Gjengedal *et al*., 2010). The telephone survey to compare the use of patient diaries in Sweden since their introduction in 1991 identified that 75% of their 85 critical care units used patient diaries with 65 of these having used diaries for almost 7 years (Åkerman *et al.,* 2010). However, all the survey findings indicated that there was no consensus on the approach to diary use; they also stated that the effect of diaries on patients remains unknown and advocated further research (Egerod *et al*., 2007, Gjengedal *et al*., 2010, Åkerman *et al.,* 2010).

More recently diaries have been adopted in the UK (Combe, 2005, Robson, 2008, Jones, 2009a, Hale *et al.,* 2010, Jones *et al.,* 2010). The numbers of critical care units currently using patient diaries in the UK is growing as a result of Regional

Critical Care Network discussions, Scandinavian publications and conference presentations. The actual extent of use of patient diaries in critical care beyond the Scandinavian survey data remains unclear. Indeed Nydahl *et al*. (2010) attempted to replicate the Scandinavian surveys in Germany only to find that no critical care units in his chosen geographical areas had even heard of them. In the UK diaries have been introduced in a sporadic manner over recent years, but currently there is very little UK based research.

Despite nearly two decades of diary use in critical care units in Scandinavia there remains no consensus on the criteria for allocation and commencement of the diary or indeed on the structure, compilation, handover or follow-up processes aligned to them (Egerod *et al*., 2011b). Furthermore in the UK there has been a slow adoption of diaries without evidence based research or consensus on how to develop and support the process.

2.4 Diary implementation

It appears that key individuals act as the catalyst for diary use (Egerod *et al.,* 2007, Gjengedal *et al*., 2010). It has been suggested that colleagues' experience or awareness of diaries were the contributory factor in units choosing to adopt them rather than the driver being research based evidence (Egerod *et al.,* 2007, Åkerman *et al.*, 2010). Motivators for diary writing tend to be members of diary teams. Diary teams, described in the evaluation of implementation of diaries and use in a UK hospital by Jones (2009a), are described as providing a means of quality control

regarding standards of the diaries. Jones (2009a) described the diary team nurse's proof reading, editing diary entries if necessary and providing clarification if needed, prior to handover to the patient and this is supported by Gjengedal *et al.* (2010) observations of nurses involved in diary use during her study conducted in Norway.

There is variation in diary allocation criteria amongst critical care units with most stating that a diary is commenced on any patient expected to stay more than 2-3 days in critical care requiring ventilation and sedation. This group has been identified as most likely to suffer memory distortion or amnesia (Egerod *et al*, 2007, Åkerman *et al.*, 2010, Gjengedal *et al.*, 2010). A concern for nurses trying to implement diary use is that literature currently demonstrates a disparity in diary implementation processes (Åkerman *et al.*, 2010, Gjengedal *et al.*, 2010, Egerod *et al*., 2011b). Primarily it highlights that diaries are being adopted without nurses and HCPs understanding what patients' perceptions and needs may be following critical illness (Ullman *et al.*, 2014, Ullman *et al.,* 2015). Each diary team uses their own approach and learning from other people's diary experiences about what does and does not work, is not always evident from the literature (Jones, 2009, Egerod *et al*., 2011b). According to this initial literature review diary use has been limited to ventilated and sedated patients and so there is no evidence concerning diary use in other types of critical care patients.

Combe (2005) in a qualitative combined prospective and retrospective study of diary use that included a prospective sample (*n*=25) and retrospective sample (*n*=8) in the research study of patient diaries highlighted that retrospective diaries can feel

impersonal as they look back at what has occurred. There is also the risk that a retrospective diary entry is less accurate as it is written after the event and is reliant on the accuracy of someone else's documentation and not necessarily the bedside nurse involved. There is a statistically significant discrepancy between numbers of diaries reviewed and it would perhaps have been beneficial to have explored the retrospective element of diary use further. In the study retrospective diary entries by nurses were perceived as being impersonal because the nurses found it difficult to capture the patient perspective in the narrative they provided (Combe, 2005). However, this could potentially have been corrected with some training. It is possible that retrospective elements of diary writing need to be included in order to provide the coherence that patients may seek about the missing time in critical care.

Prospective diary writing (written at the time for the patient to read in the future) appears in the literature to be the method of choice with entries completed as closely as possible to the event being documented. It is believed diary writing should aim to capture the situation while it is fresh in the mind (Egerod & Christensen, 2009). However, with the criteria for commencing a patient diary being cited as after 48-72 hours in the literature, it could be argued that the life threatening phase of the patient's admission to critical care could have been omitted from the diary. This could negatively impact on the story that the diary provides for the patient. In this situation surely a retrospective element is essential to provide that crucial missing part of the patient journey.

It was identified that diaries can be ambiguous with variation in the way they are structured. Concern was raised about the lack of information regarding diary use and evaluation of their effect with no follow-up process in place. Egerod *et al.* (2007) suggested that diaries were being introduced in an experimental manner rather than as part of a therapeutic measure and consideration about follow-up support or evaluation of diary effect.

It was proposed by Egerod *et al.* (2007) that National Clinical Guidelines on diary use should be developed to provide agreement and uniformity in the patient diary approach. However in 2009 Egerod & Christensen argued that use of guidelines could affect the voluntary and spontaneous approach to diary writing and confine nurses' writing. They obviously changed their view again and went on to develop National Guidelines in Denmark (Egerod *et al.*, 2011a, 2011b). These guidelines were used as part of the randomised control trial incorporating six countries (Jones *et al.*, 2010). Currently there remains disparity in the criteria for allocation of a diary and indeed diary construction (Egerod *et al.,* 2007, Gjengedal *et al.,* 2010, Åkerman *et al.,* 2010, Egerod *et al*., 2011b). The challenge of agreeing on the patient diary approach remains; and will arguably continue until patients have a voice in their evolution.

In some places diaries are photocopied and filed in the medical notes for future access by the patient or they can be destroyed after twelve months has passed (Jones, 2009a, Hale *et al.*, 2010). However, a note of caution has been raised: some patients who do not collect their diary do make contact around the twelve

month anniversary of their illness wishing to access it (Jones, 2009a). Human beings have different needs and ways of coping at different timeframes in their life and it is difficult to predict when or if, the critical care diary may, or may not be, of use to the patient.

Empirical evidence in the literature suggests patients like to see visual images of themselves in the critical care environment; including staff and family members (Bergbom *et al.*, 1999, Bäckman & Walther, 2001, Jones, 2009a, Jones *et al.*, 2010). Bäckman & Walther (2001) felt that a detailed narrative of events during critical illness formed a useful debriefing tool for patients, enabling them to cope with their experiences through using the diary and photographs as a guide to explain the patient's journey through their illness. It provides a source of information beyond the second hand detail that their relatives would normally supply (Egerod & Bagger, 2010). It was also highlighted that photographs and dialogue provide an insight for the patient that would otherwise be hard to capture (Bäckman, 2011).

According to Jones (2009a) it is important that the content is appropriate for the patient to read and any writing that may be misunderstood is clarified or edited appropriately. Editing implies censorship of material. Gjengedal *et al.* (2010) espouse that authors of the diary continue to develop this skill of narrating for another and that legal, professional and ethical aspects need to be balanced; arguably without compromising authenticity (Phillips, 2010). However, there is little available on this important facet of diary use.

What is documented may lack enough detail and one criticism of the diary has been that nurses reflect their actions as opposed to patient reactions (Gjengedal *et al.* 2010). Some patients have noted that the diary has failed to capture key episodes of their critical illness and behaviour, which has left them feeling concerned. They had hoped the diary might shed light on why they were agitated or aggressive during their illness, but this depth of material was not forthcoming and the diary has been accused of glossing over or neglecting serious life threatening episodes (Egerod & Bagger, 2010). Therefore careful consideration of what to include and how to incorporate the information in a tactful manner is required by those who contribute to the diary. Capturing good practice in diary authorship is difficult, possibly because it is unclear what the standard for good practice should be without further research to support the developing body of knowledge related to diary use.

Further research is required to determine the impact of the vicarious diary writer in terms of how and what they write and choose to include or exclude and the potential differences in style and content. These factors may impact on the meaning of the diary for the patient. Therefore, it can be argued that the diary will only be as good as its authors. Capturing the nurses' and other HCPs understanding of diary use and ensuring the diary meets patient expectation is pivotal if they are going to be used as part of a psychological support process.

It has been highlighted that diary entries need to be clear and jargon free as it is being written for the patient to read and to make sense of their admission to critical

care (Bäckman & Walther, 2001, Combe, 2005). Some diaries have included the use of a glossary of terms and even labelled photographs of equipment with the aim of enhancing the descriptions provided in the diary (Jones, 2009a). Dialogue can be provided for every day so that a chronological portrayal of the critical illness is evident and reflects patient milestones and progress or deterioration (Bergbom *et al.*, 1999, Bäckman & Walther, 2001, Jones *et al.*, 2010).

The current situation in the UK remains subject to variability in diary practice, and is dependent upon key individuals or diary teams who drive the process forward (Jones, 2009a, Hale *et al*., 2010). Further research is required to determine what information is useful and how dialogue should be provided to optimise the perceived 'value' of the diary for patients.

Knowles & Tarrier (2009) conducted a small pragmatic RCT in the UK (*n*=36) aiming to evaluate the effect of prospective patient diaries on emotional well-being in critical care survivors over a period of a year during 2006-2007. The study included patients who had been in critical care for more than 48 hours. They were randomised to either a control group who did not have a diary kept on their behalf, or the intervention group for whom diaries were kept; these included entries about patient's physical condition, any interventions and key events both in critical care and occurring in the outside world. They hypothesised that recent critical care patients receiving a diary would show less symptoms of emotional distress after one month in comparison to the control group. During the timeframe of the study there were *n*=115 eligible participants identified; of which 40 died before they could be included. This

left *n*=75; of which *n*=14 were not eligible, *n*=9 were transferred, lost contact details or readmitted to hospital. This left *n*=52 with *n*=16 declining and *n*=36 enrolled on the study. The control and intervention groups consisted of *n*=18. The initial assessment using the hospital anxiety and depression scale (HADS) identified that half of the patients fitted the disorder likely category (*n*=16 scored 44% for anxiety and *n*=17 scored 47.2% for depression). These results are not surprising given they were elicited after one month following ICU admission. The second phase of assessment, was conducted three weeks after the first, results demonstrated a reduction in symptoms in the intervention group. There are a few concerns related to the reliability and validity of this study, firstly there is a lack of a study protocol or clinical trial registration.

Participant numbers are low for an RCT and this leaves the results open to scrutiny. Ideally a larger sample size would have given the results more credibility and it is unclear if the significance level was adjusted with this in mind or not. The principal Investigator conducted the psychological assessment and was not blinded, increasing risk of bias. There were crucial differences between the control and intervention groups regarding length of stay and APACHE II scores, both of which could lead to increased risk of PTSD. The timing of assessments is too close to the event to be representative of emotional impact over time post ICU admission.

Diaries have been described as a debriefing tool for patients who have been ventilated and sedated, as well as a means of trying to alleviate memory deficits and psychological symptoms by aiding in the setting of realistic goals for recovery. This

is achieved by ensuring the patient understands the reality of the implications of their critical illness (Backman & Walther, 2001, Combe, 2005, Robson, 2008).

The diary as a debriefing tool was explored by Jones *et al.* (2010) in the RACHEL group Randomised Control Trial (RCT) (RACHEL stands for Raising Awareness after Critical Illness of Adverse Health Events in the Long term). Jones *et al.* (2010) European (6 countries with 2 ICU s per country) pragmatic RCT (*n*=322) suggested that the use of a diary kept by nurses and/or the multidisciplinary team is effective in reducing symptoms of new onset (associated with their critical care admission) PTSD. However, criticisms of the RCT include multiple methods of assessment used to establish symptoms of PTSD and the lack of experience of the researchers in this specialised process. Scrutiny of their RCT has found the method of collecting the data did not meet the expected standard of a clinically conducted interview carried out by someone with expertise. The blinding process of participants and researchers is a concern as they describe it being impractical as patients volunteered their use. Furthermore they described a lack of training at three month follow-up with researchers trained in interview and administration of the post-traumatic diagnostic scale, with participants providing a self-completed questionnaire. The study timeframe of data collection all within a three month period does not allow for representation of psychological changes over time and a longitudinal approach may have increased validity of the study. Therefore the study findings are deemed inconclusive.

Bäckman *et al*. (2010) in a non-randomised prospective RCT hypothesised that use of diaries would improve patients' health related quality of life (HRQoL) by filling in gaps in memory following critical illness requiring critical care admission. The study was conducted with *n*=38 participants who had diaries kept on their behalf compared with *n*=224 who did not have a diary. Findings suggested that the diary enabled the patient to re-orientate from critical illness to normal life and it is possible that more realistic goal setting has a positive influence on physical recovery (Bäckman *et al.,* 2010). However, the use of historical records and the disparities between the two groups studied in terms of age, size and severity of illness call into question the reliability and validity of the findings and the authors do note that a larger and randomised study is required. Research using appropriately selected and consistent approaches that can be compared is required.

Sustainability of critical care diaries has been a subject of concern in the literature. A Norwegian qualitative designed survey, using semi-structured telephone interviews identified that diary writing can vary with staff over time with some only writing sporadically (Gjengedal *et al.*, 2010). Participation in diary writing is generally described as being on a voluntary basis (Jones, 2009a, Hale *et al.* 2010). Jones (2009a) stated that when diaries were introduced in one unit they formed a diary interest group in order to facilitate the process. The use of diary teams seems to form the sustaining element of the diary process and there is concern that not all patients who should have a diary actually receive one (Gjengedal *et al.*, 2010). If the process is voluntary and investment in it is subject to variability amongst staff, then this is a concern in regard to sustainability of the critical care diary process.

The handover of the diary to the patient has been described as an opportunity for clarification and explanation (Jones, 2009a). However the handover process and provision of follow-up support were described as inconsistent in the literature. Indeed according to Åkerman *et al.* (2010) in another in the series of Scandinavian qualitative descriptive survey studies, some critical care units were unable to explain the purpose behind use of a diary. Instead data identified that diary implementation had occurred through colleagues interest in diary use rather than on research based evidence (Åkerman *et al.,* 2010). It is a concern that diary use without an underpinning purpose has been adopted in critical care units (Egerod *et al.*, 2011b). The risk is that diaries have limited value for the patient if those involved in writing them do not understand their purpose. Indeed that the diary could prove harmful for some patients unprepared for what HCPs may tell them in their entries.

According to Engström *et al.* (2009) in a study using qualitative personal interviews (*n*=9), reading the diary is painful and demanding for patients and she advocates use of follow-up support beyond that of a one off event at diary handover. The study uses small numbers and as a qualitative study provides useful insight, but more research is indicated to explore the implications of a dairy as a source of difficulties for patients in the form of being painful and demanding for them to read. The psychological impact on critical care patients, associated with knowing what has happened needs to be investigated. What has been identified is that diary use alone may provide incomplete information and should be provided in tandem with provision of follow-up (Egerod & Bagger, 2010; Gjengedal *et al*., 2010). This means that HCPs

would be ill advised to adopt diaries as a quick means to address the mounting awareness of psychological consequences of critical illness for patients. Critical care diary implementation needs careful consideration to avoid leaving patients potentially unsupported in dealing with the aftermath of reading the contents.

2.4.1 Nurses and diary writing

For nurses and other HCPs there is the potential vulnerability of writing events in a diary for the patient and their accountability in participating in this process. According to Egerod & Christensen (2010) in a qualitative, descriptive, comparative design study exploring 25 patient diaries and interviewing *n*=10 patients, diaries are very different to hospital records and serve a different purpose. They identified that diaries were perceived as personal and supportive, while hospital records were technical, fragmented and impersonal. This highlights that writing in a patient diary is not an easy task for HCPs. Knowing what to include or omit, and how to say it, is not simple and support, explanation and training of staff is required when implementing critical care diaries.

Storli & Lind (2008) conducted a qualitative hermeneutic- phenomenological study based on participants attending follow-up. Initially they made field notes from *n*=10 patients attending follow-up appointments at three months. Next they interviewed *n*=8 patients at six months and finally *n*=6 at eighteen months post-ICU discharge. It is interesting to see how participant numbers reduced over time. While drop out may

be congruent with most longitudinal studies, perhaps it also indicates the enormity of the impact of critical illness for the individuals involved.

Storli & Lind (2008) concluded that the diary is associated with 'normalising' by helping patients understand the source of strange experiences or memories. The nurse who discussed the diary with the patient is described as important as a 'qualified listener' who knew what the patient had been through and gave them time to question and understand events described in the diary without being 'dismissive' of the dreams and memories of the patient. The diary, according to Storli & Lind (2008), is also seen as a means of 'confirming patient experiences'. In agreement, Egerod *et al*. (2011a) describe the diary narrative as providing a way for the patient to confront and confirm their illness journey through reconstructing the events and making sense of them. Another aspect the Storli & Lind (2008) study mentions is returning to the critical care environment and the bed space and enabling sensory experiences to be related to the environment. The researcher feels that it has to be noted that not all patients would want to return to the critical care environment and such a decision needs to be the patient's choice. As noted previously there is the concern that not all patients may wish to explore what they cannot remember. In HCPs efforts to acknowledge critical care survivors experiences and psychological needs care needs to be taken to avoid unintentional harm.

Gjengedal *et al.* (2010) in their qualitative descriptive study, using semi-structured telephone interviews, found only 10 units (*n*=30) described diary writing as a significant investment of their time and the rest suggested writing varies over time to

sporadic writing, with only a few patients who may benefit from a diary actually receiving one. A few units included other HCPs in diary writing, but most included relatives' entries either directly into the diary or on separate sheets. The paper a patient used to write on to try to communicate was seen as significant by some units and nurses would include them as part of the diary and comment on these. This fits with Riers (2000) development of a diary while he was a patient. Some nurses suggested that writing a diary for a patient improves the care they provide as the writing changes from medically orientated to a more 'human' style and there is an increased awareness of patient facial expressions and nursing interaction as a result. Gjengedal *et al*. (2010) refer to this as awareness of the patient as a person. Potentially then a diary could act as a vehicle to capture the relationship between nurse and patient for them to look back on during their recovery.

It is advocated that patient diaries should try to capture key events/ milestones patients have achieved (Bäckman & Walther, 2001, Egerod & Christensen, 2009, Gjengedal *et al*., 2010). However this is not always feasible and some nurses may choose not to contribute to patient diaries. Diary writing should be on a voluntary basis as enforcing it on people would risk negativity and could impair the quality of the diary for the patient (Jones, 2009a). This could potentially leave gaps in the chronological story expected by the patient.

Titchen (2001) describes the nurse patient relationship in terms of a 'Skilled Companionship Model'. This is not something previously applied to diary use, but it captures elements described in existing diary literature. The Relationship Domain of

this model provides useful insight that a nurse could draw on to support development of the nurse patient relationship in terms of writing a diary on behalf of the patient. Arguably if the diary is for the patient to read during their recovery it needs to capture how the nurse looked after them, what interactions occurred, not only health related needs, but considerations they made for that person as an individual as noted below.

Titchen describes ‘Particularity’ as knowing the patient in terms of their illness and context of their lives. This involves two ways of knowing; firstly knowing the patients’ responses and how they function physically. Secondly knowing how patients may feel; perceptions, beliefs, thoughts, expectations, memories, attitudes, meanings and self-knowledge about and interpretations of health and illness. The nurse needs awareness of the patient experience of illness and concerns and of significant social relationships, life events and experiences. Consideration needs to be given to how the nurse understands the critical care survivor’s perspectives through their experiences and recovery. Integration of patient stories and their feedback into training and education may be beneficial to provide insight. Actually being involved in meeting critical care survivors and their family may have more impact than reading about it and could facilitate the stage outlined below.

Reciprocity is described by Titchen (2001) as an exchange of concern, knowledge and caring that occurs in a close interpersonal nurse patient relationship. It is possible that vicarious diary writing enables the nurse to express this concern. Mutuality refers to a dual effort in nurse and patient meeting needs and is the forming of a genuine relationship which again can potentially be demonstrated

though diary dialogue. Graceful care is reference to the nurse using their own physical, humanistic and spiritual ability to promote the health and recovery of the patient. This could be attained through the little touches such as art, poetry and words used within the diary (Gjengedal *et al.,* 2010). Finally Titchen (2001) notes the need for 'authenticity' of the nurse in delivery of care and in the forming of a genuine relationship with the patient.

Therefore, a diary initiated and written on the patient's behalf by the nurse could provide a means of facilitating the connections required in a functional nurse patient relationship, especially as critical care survivors may have little or no memory. Understanding the purpose of a critical care diary is fundamental to the nurse and their involvement in the process. Current literature identifies diversity in the manner in which nurses implement diaries and consensus on approach is lacking, possibly because existing research fails to build on the body of knowledge in favour of replication of what is already known.

Diary entries should reflect what the patient may want to know during recovery, but there is very little information to provide guidance on what patients need from their diary. Further research is required to establish the desired content of a diary for patients and the missing connection it has potential to provide between nurse and the patient who has been unconscious and unaware of the interactions involved. Roulin *et al.* (2007) describe the diary as conveying commitment and care provided by nurses. It is possible that diaries provide a unique insight into the nurse-patient relationship: the diary as a window to nursing care and as such nurses need to be

mindful of the professional responsibilities and accountability associated with diary use (Nursing and Midwifery Council, NMC, 2015).

2.4.2 Legal and professional considerations

A fundamental concern regarding diary writing on behalf of a patient is that, unlike nursing and medical notes, a diary is currently not perceived or supported to be an essential part of patient care or a legal requirement. Therefore the diary forms a record of non-essential clinical data. It is important to note that a critical care diary may be potentially either beneficial or harmful for some patients depending on many factors; one of which is the manner in which it is written.

In terms of a patient diary, the author (be that a nurse, other HCP or relative) needs to remember that it is the patient's diary and not their own and therefore, what is written 'vicariously' requires more consideration than traditional diary keeping for one's own benefit. Egerod *et al.* (2007) stated that patient diaries are ambiguous documents; they are neither the property of the hospital nor the patients and they identified that legal and ethical issues remain to be resolved. According to Åkerman *et al.* (2010) the diary is described as the patient's property and 35% of critical care units surveyed had sought ethical/legal advice regarding diary use. Egerod & Christensen (2009) say that diaries expose and hide information and this will be reliant upon the author, their knowledge and understanding of the diary purpose and confidence in writing for another in a more personal manner. They also state that

diaries provide new insight into nurses' performance in the context of caring for the patient.

In diary writing nurses may censor what they say as they do not want to cause further trauma to the patient reading the information (Jones, 2009a). The diary can be too superficial for some people (Gjengedal *et al*., 2010). There is not necessarily a feedback mechanism for nurses on patient's perceptions and experiences of their diary (Egerod *et al.,* 2011a). If there was feedback perhaps this could increase HCP engagement in the process and to adapt and enable the diary to evolve to meet patient's needs. Therefore in some cases HCPs may feel a diary is unhelpful when they have patient care to prioritise and it can be perceived as another paperwork burden (Nydahl et al, 2010).

Egerod *et al.* (2007) noted that HCPs who choose to make diary entries must avoid 'intimacy' with the patient, referring to the need for professionalism. Gjengedal *et al.* (2010) called it 'candour' and 'avoiding offence'. Egerod & Christensen (2009) question whether nurses should be confined to guidelines if writing the diary is voluntary. Conversely without guidelines, nurses could be opening themselves to potential complaints or litigation. A diary could form evidence as part of a complaint or concern about care.

A consideration for the HCP is the potential vulnerability of writing events in a diary for the patient and their accountability in participating in this process. Gjengedal *et al.*

(2010) states that diary entries should be professional but narrative and should be addressed to the patient. Entries should be dated and signed. This could imply accountability is being taken for the content of the documentation (NMC, 2015). It is also a means by which the patient can identify a name of a nurse who cared for them and is potentially important to the missing nurse-patient relationship.

There is potential for patient diaries to be a source of 'judgment' regarding standards and quality of care and the service provided to the patient. In which case, the nurse can be held to account (NMC, 2015). An element of self-control or self-governance (censorship) regarding what is written by nurses may occur to avoid perceived potential complaints or litigation. The process of selective dialogue or self-governance and control (censorship) may restrict the openness of information provided for the patient, there is a need to balance professional integrity, to avoid complaints and litigation, with the best interests of the patient and an authentic account of their critical illness journey. Nurses are bound to feel some reservations about how 'exposed' they wish to be in their diary entries. As noted by Egerod & Christensen (2010) earlier in the chapter, at present hospital records and diaries serve different purposes for patients, and the differentiation is significant. If critical care diaries were to become a means for complaint about care this could derail the idea.

Currently relatives are approached for consent to commence the diary on behalf of the unconscious patient, with retrospective consent being sought from the patient when they are able to be asked e.g. at diary handover (Jones, 2009a). There is

vulnerability in not having patient consent for something which the patient may not want and in the interim requires holding potentially confidential data on them (Data Protection Act, 1998). If the family are invited to participate in writing in the diary then there is a potential conflict regarding what can and cannot be included and if the patient would want that individual to contribute to the diary and read the content of the diary. Potentially the relatives use the diary during the patient stay in critical care, but the patient may never wish to see it. There is also the potential for relatives to misconstrue the purpose of the diary and anecdotal evidence suggests some have used the diary as a source for raising complaints about care.

There is a concern about how long the diary should be held before being destroyed and there appears to be some variation in practice related to this. Currently it appears that the diary teams, who choose to participate, police the diary. It could be argued that the medical notes, which can be accessed by the patient using the Data Protection Act (1998), would suffice in terms of follow-up and explanation of the patient's critical illness. However, the alternative view would be that the diary adds context and is written in a 'patient friendly' manner that differs significantly from medical notes (Egerod & Christensen, 2010).

Aspiring to help patients' psychological well-being is a worthy position for nurses and other HCPs to hold. However providing a diary with lack of explanation or follow-up could have a detrimental impact. Therefore diary implementation requires strategic planning, education and preparation of those who wish to contribute. It also needs investment in follow-up provision.

2.5 Theories about critical care diaries

There are three distinct themes that can be derived from the existing research. One refers to the continuing struggle to gain a consensus on allocation criteria and structure or compilation of the diary used in the realms of critical care (Åkerman *et al.,* 2010, Gjengedal *et al.*, 2010, Nydahl *et al.*, 2010, Egerod & Bagger, 2010). The second pertains to the diary and potential impact on the psychological well-being of the patient in terms of quality of life and reduction of symptoms related to anxiety, depression and PTSD (Knowles & Tarrier, 2009, Jones *et al.*, 2010, Bäckman *et al.* 2010). The third theme that is evolving surrounds the exploration and understanding of the diary narrative or dialogue (Egerod & Christensen, 2009, Gjengedal *et al.*, 2010). This has led to a few theories about critical care diaries.

One theory is that the diary demonstrates caring and keeps the focus on the patient as a human being or person (Egerod & Christensen, 2009, Storli & Lind, 2009). This would be dependent upon the manner and content provided in the diary entries. Anyone implementing critical care diaries would need to consider what works and what does not for patients and currently there is little research on what patients feel this entails.

A critical care may convey the commitment and care provided by the nurses and may include personal touches for the patients to read (Roulin *et al.,* 2007). However it is also possible that a diary could be too superficial or has key HCPs who did not

contribute and this could cause a patient to question the commitment and care they actually received. Instead of providing reassurance it could be counterproductive.

Therefore critical care diaries are reliant on the way in which the diary narrative is written. According to Storli *et al*. (2008) and Egerod & Christensen (2009) a critical care diary can give meaning to potentially meaningless experiences. A concern with this perspective is that some people prefer to cope with stressful or traumatic situations by not knowing what has happened. Although critical care diaries may be being introduced with the best of intentions the outcome may sometimes be harmful rather than beneficial.

Another theory pertains to the diary as provision of therapy or as a debriefing tool, in that it enables a void in the patient's memory to be filled by providing objective information and orientating the patient to reality (Hupcey & Zimmermann, 2000, Bäckman & Walther, 2001, Combe, 2005, Jones *et al.,* 2010). The National Institute of Health and Clinical Excellence (NICE) and Cochrane Review (Rose, Bisson & Wessley, 2007) based on the results of 11 randomised control trials (RCTs), do not recommend one-off debriefing sessions following a traumatic event. Three of the eleven studies associated debriefing as a positive experience for patients whereas six studies identified no benefit and the remaining two studies identified debriefing as having a negative outcome for patients. Studies indicate that debriefing needs time and should not be rushed as time limiting a session can exacerbate problems. Arendt & Elklit (2001) identified five studies with debriefing lasting over an hour and

having a positive effect as oppose to six studies with a negative effect associated with sessions lasting less than an hour.

Timing of the debriefing needs consideration as debriefing too soon after a traumatic event is seen as detrimental as it is associated with negative patient outcome. Interestingly Mayou *et al* (2000) conducted an RCT in survivors of traumatic road traffic accidents and found that the control group fared better than intervention group who had received debriefing as their intervention. However, the intervention in the form of debriefing was conducted in the first 24 hours post event. It is recommended that debriefing is avoided in the first 24 hours post traumatic event resulting in injury due to this associated negative impact on patients and the Mayou *et al* (2000) study participants probably needed more time to pass before debriefing was initiated and also the debriefer needs to be trained and experienced whereas the research assistant had to take over in the Mayou *et al* (2000) study.

Everly & Mitchell (1999) advocate debriefing between 24 hours and 10 days after the crisis, but never in the first 24 hours. It is believed that forcing someone to relive a distressing event in the initial period after it has occurred can actually embed vivid memories and negatively impact upon their recovery. However according to Everly & Mitchell (1999) if the event is deemed catastrophic then debriefing should take place after 3-4 weeks has passed.

In the context of provision of a critical care diary for a patient as a means of debriefing there have to be concerns about how the process is conducted to try to mitigate for potential harmful effects of reading about something of which they most likely have little or no memory.

Currently the literature fails to consider the potential harmful effects of providing a critical care diary or the supportive processes that should be integral to provision of a diary. Existing studies suggest only a few ICUs use diaries in conjunction with on-going follow-up opportunity for patients. It is almost perceived by HCPs as an easy option instead of the expense of follow-up provision (Egerod *et al*., 2011b).

2.6 Research gaps

Research has failed to focus on patients' views of the diary, how they feel about it, how they interact or engage with it. Researchers have tended to discuss diaries in terms of impact on the patient's psychological health and follow-up support without first identifying the patient perspective. Diary use seems to have escalated with little insight into what they do, if they work and if so in what ways. A trend from the literature is that the patient view is secondary to the main study focus and it is a fundamental requirement to establish the patient's views in order to ensure that diary use is appropriate and if so, that it evolves with the patient in mind to meet their needs.

The potential risks associated with keeping a diary on behalf of a patient cannot be ignored. Indeed these factors need to be considered in any future development of diaries in critical care to ensure that any potential harm that could occur is avoided or a least minimised. The following concerns are identified from the literature:

- Limited knowledge and understanding by those writing in the diary; be that nurses, other HCPs or relatives and friends. Therefore a lack of training may exist regarding diary use in terms of its role and purpose.

- A lack of research to support diary use and representation of the patients' views and what they feel they need from a diary makes the diary a subjective entity that is open to scrutiny and which may or may not meet patient needs or expectation.

- Resources, time and commitment to diary compilation have been described as deteriorating over time or dependent upon individual staff views or assumptions and this raises concern over the sustainability of the process in the long term. It also highlights a potential disparity in equity of diary use for patients.

- Using a diary without appropriate support mechanisms in place, for example follow-up meetings: how frequent they should be, who should run these and what psychological and physical referral processes need to be in place.

- The authenticity of the diary with consideration of meeting patient expectation. There are risks of paternalism and censorship by authors having a direct influence on the coherence of the narrative (the story) for the patient.

- The risk of exposing a patient to diary content which may actually trigger a psychological concern where there was not one previously. There is a fine line between restoring a patients' memory and actually interfering with their natural coping mechanisms, such as not wanting to remember. It is important that future research consider if diaries actually work and if so in what circumstances whilst also considering the potential for a diary to be detrimental to some and in which circumstances.

A trend from the literature is that the patient view is secondary to the main study focus, when it should be the primary concern. Researching critical care diaries without first establishing patient perceptions has created an intervention that lacks a

robust evidence base to support its use. Questions that need to be asked refer to the diary content and what patients feel is beneficial to them. Also consideration needs to be given to what triggers the patient to want to read their diary, or not, at what point and in what circumstances. It needs to be established when the patient would like to have their diary and how they feel the handover process should be managed. Furthermore patients' views about follow-up provision are important.

There appears to be a core of researchers interested in diary use who have published papers, often working collaboratively on material, which introduces researcher bias that may undermine the clarity of the research based evidence (Egerod *et al.*, 2007, Egerod & Christensen, 2009, 2010, Jones, 2009a, Jones *et al.*, 2010, Bäckman *et al.,* 2010). They have provided insight into the many facets of diary implementation and use, but impartial evidence is required to help create a body of evidence to help diaries evolve to meet patient needs. Research priorities need to be identified and good quality qualitative and quantitative research studies developed that provide the missing consistency of case mix, valid tools of data collection using robust methods and selecting similar participant groups to aid comparison.

- There is currently minimal representation of the critical care patient in the development of the diary process.
- Research is required to establish views of patients who collect their diary.
- The views of patients need to be explored over time to capture potential change in perspectives and insight into diary use during the recovery phase.
- The role the diary may play needs further exploration and explanation

The existing research regarding diary use is of poor quality be that quantitative or qualitative studies (Ullman *et al*., 2014). The Scandinavian series of studies using telephone surveys were replicated with limited influence on the diary process and no representation of patient views (Egerod et al., 2007, Åkerman *et al.,* 2010, Gjengedal *et al.*, 2010, Nydahl *et al.*, 2010). Even the RCTs noted in this chapter had impeded impact due to the methods of data collection and an inability to compare studies due to the diversity of approaches used. There is a lack of longitudinal studies conducted which would be beneficial in representing the initial year of recovery critical care survivors face and where the most changes can occur (Agård *et al.,* 2012). Hence the research focus for the current study needed to start with capturing the patient voice and using a longitudinal approach to capture any significant changes during the first year of recovery.

The current study will focus on an in-depth longitudinal insight into critical care survivors' experiences of critical illness, recovery and use, or not, of their diary during this process. Patient perspectives of critical care diaries are lacking in the current literature. Diary use needs to be based up on what works for patients instead of on assumptions made by nurses and other HCPs in order to provide a scientific basis for critical care diary use.

2.7 Reflexivity

Arguments against a literature review at an early stage are posed around preventing constraint, contamination or inhibition in the researcher. This, it is proposed, prevents recognised or unrecognised assumptions forming and also prevents the focus from being on the literature rather than the emerging data. The researcher, as a novice, admits to an initial inability to see the broader implications of her area of research and it was hard to detach herself from a focus on the diaries and to be open to the stories of critical care survivor experiences.

There were times when literature was interesting and then it was difficult to separate that from what participants had to say and to ensure analysis maintained the original integrity of the data.

2.8 Summary of chapter

The value of a diary for critical care patients has yet to be established. Research tends to focus on the assumption that critical care diaries are purely beneficial and more work is required on identifying any potential harmful effects associated with critical care diary provision.

The diary may or may not capture information that the patient can use to gain clarification of events at a later date. Patients do not have central control concerning the diary which is intended for their use after discharge from hospital to home.

Guidelines and best practice in relation to diary use remain undefined and therefore it can only be assumed what patients want from their diary and it is vital to establish this to inform future development of diaries.

A lack of consistency and robustness of studies render comparisons and extrapolation of the role of a patient diary a challenge for HCPs to comprehend. The lack of clarity about diary implementation, structure and content adds to the potentially haphazard approach taken by well-meaning HCPs. A lack of knowledge and understanding of the purpose of critical care diaries and patient's needs and interactions with their diary during the recovery process means there is a danger that rather than being beneficial the diary could be harmful for some patients. Research in to critical care diaries needs to be strengthened though ensuring the quality in both qualitative and quantitative approaches with consistency of case mix, validity of tools used for data collection and using each study to inform the next to build a series of research that contributes to the developing body of knowledge about critical care diaries. Since conducting this initial limited literature review, in keeping with GGT, there has been additional research which has been integrated within the findings chapters.

Chapter 3: Methodology and methods

3.0 Introduction

The methodology is a series of choices, outlining the research approach taken by the researcher (Polit & Beck, 2012). The methodology is the systematic process used to address the study purpose and informs the choice of research methods adopted by the researcher. It should provide a logical explanation for selection of methods used to conduct the study and rationale for rejection of other research methods. This enables the researcher's decisions and findings to be open to evaluation by the researcher and others (Parahoo, 2014).

This longitudinal qualitative study requires depth and insight regarding critical care survivors' perceptions of their diary and initial twelve month recovery period, in order to develop a detailed understanding of their experiences and the implications these may have for developing theory and future diary use.

In the current study the research questions, aim and objectives identified are:

Aim: To provide in-depth insight into critical care survivor experiences and use (or not) of a critical care diary during the first 12 months of their recovery to inform development of theory and future diary use.

Research questions:

- What are patients' experiences following critical illness?
- What role, if any, do diaries play in their recovery?
- What insight does this provide for future critical care diary use?

Objectives: To critically explore participants':

1. Experiences of critical illness and their ensuing recovery during the first 12 months.
2. Use of their critical care diary (or not) including if, when, and how they used it and to elicit how diaries may be useful at different time points during their recovery and rehabilitation.
3. Perceptions of diary content (type, breadth and depth), impact of this and role, if any, they felt their diary had for them during their recovery.
4. Environmental and demographic factors that may impact on perceptions of the diary.

Having clarified the focus of the study this chapter will explore how best to conduct the study and key methodological decisions made. An exploration of paradigms and selection for this study will be provided to clarify the researcher's structure of inquiry and methodological choices. Data analysis, research design and ethical issues are explored.

3.1 Research paradigms

The first stage in formulating the research design requires the researcher to determine their ontology. Ontology can be described as what constitutes reality and how existence can be understood (Parahoo, 2014). In a research context this requires the researcher to decide whether they approach their study from an objective or subjective position. An objective perspective considers reality as consisting of solid objects that can be measured and tested, while a subjective perspective looks at reality consisting of perceptions and interactions of living subjects (O'Gorman & MacIntosh, 2015). Social Sciences tend to use an objective ontology to study and explain universal principles and facts through robust and replicable methods. A subjective ontology is used to explore variation in human behaviour, interaction and experiences in relation to a chosen topic. Subjective ontology perceives that there are multiple realities in the context of differences in how an individual experiences their place and time in the world (Parahoo, 2014).

Epistemology can be described as what constitutes valid knowledge and how it can be obtained (Parahoo, 2014). An objective ontology is typically aligned to a positivist epistemological approach to knowledge, while a subjective ontology tends to be based on an interpretivist epistemology. Positivists posit and explain principles, while interpretivists interpret and understand relationships (O'Gorman & McIntosh, 2015). An objective ontology with a positivist epistemology generally represents a quantitative methodology. A study that expresses a subjective ontology and an interpretivist approach tends to represent a qualitative methodology (Draper, 2004).

Qualitative research can facilitate the opportunity to pose difficult and sensitive questions that do not fit with the precise measurements associated with quantitative research. Using an interpretivist epistemology facilitates use of methodologies that enable the inductive and holistic gaining of greater understanding. It provides explanation of human experiences and phenomenon, as opposed to seeking external causes or principles (Parahoo, 2014). Interpretivism is associated with methodological approaches that aim to capture the participant voice, concerns and interactions, which suit the context of this study (Austin & Sutton, 2014).

The objective ontology and positivist epistemology associated with quantitative research was rejected for the purpose of this study because of its objective, rigid approach required in the application of quantitative research methods. These aspects are not suited to research involving the subjective nature of peoples' experiences. Bearing these issues in mind qualitative research best fitted the area of study and the research questions identified because exploration of participant experiences and perceptions are subjective.

3.2 Grounded theory

Glaser and Strauss (1967) developed grounded theory together as a systematic qualitative research method in the social sciences, with the emphasis on generating theory from the data gathered through research using constant comparative analysis. Their seminal work '*The Discovery of Grounded Theory: Strategies for Qualitative Research'* emerged during a period when the use of qualitative

methodology was viewed sceptically and quantitative/positivist research was the focus in the scientific community (Corbin & Strauss, 2014).

Grounded theory (GT) incorporates traits from the quantitative paradigm through its systematic and methodical approach and traits from the qualitative paradigm with its inductive approach to analysis and emerging theory 'grounded' in the data (Glaser, 2008). The essence of GT is development of theories that are grounded in the data that is gathered and analysed. GT is advocated for researching topics where little is known and it forms a means of gaining in-depth insight into participant experiences (Parahoo, 2014). GT is appropriate for the current study as it is best able to achieve the research questions, aim and objectives.

There are various forms of GT and the following section will discuss them and provide the researcher's rationale for selection of the GT approach used in this study. The following section explores GT, explaining what it is, how it developed and which version was selected for the current study.

3.3 Grounded theory approaches

3.3.1 What is grounded theory?

There is some debate about what constitutes grounded theory, but it is generally described as an approach for looking systematically at data, most often qualitative in nature (Suddaby, 2006). The purpose of grounded theory is the discovery of theory

from the data which is inductively derived from the study of phenomena and is discovered through systematic data collection and analysis (Glaser & Strauss, 1967).

Advantages of using grounded theory lie in the systematic approach to data analysis that is incumbent in all versions of grounded theory. All versions require a coding process, but interpretations of how to do this differ. They all use constant comparative analysis, but there are differences in when literature is introduced to the process. The emerging theory is reliant on the identification of codes that inform development of categories and ultimately an area of core concern. These are reliant on use of researcher memos and there are differences in approaches used to achieve this.

There are three main contentions that surround the different approaches to grounded theory. These contentions arise around the *role of induction* in grounded theory (abstraction, not description) or emergence versus forcing, *discovery (or emergence) versus constructivism* and a *focus on social processes versus individual experience* (Bryant & Charmaz, 2007). The different versions of GT are explored in the next section.

3.3.2 The development of grounded theory approaches

According to Fernandez (2012) there are four main versions of grounded theory: Glaserian grounded theory (Glaser, 1978), qualitative data analysis (QDA) or

Straussarian grounded theory (Strauss and Corbin, 1990), Feminist grounded theory (Wuest, 1995) and Constructivist grounded theory (Charmaz, 2006).

Following their collaborative publication in 1967, philosophical differences led Glaser and Strauss to pursue interpretations of the original work separately. Strauss published *Qualitative Analysis for Social Scientists* (1987) followed by *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* with Corbin in 1990. Glaser (1992) contested the Grounded Theory represented by Strauss and Corbin in his publication *Emergence versus Forcing: Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Glaser argued that it was a different methodology altogether, with techniques that in his opinion did not facilitate discovery. Stern (1994) claimed the differences between the researchers had always been apparent, but it was not until Strauss published detailed guidance on GT (Strauss, 1987, Strauss & Corbin, 1990) that the differences widened. Glaser suggested Straussarian GT constituted conceptual description, not grounded theory (Stern, 1994).

Two main characteristics of grounded theory research design are constant comparative analysis with emerging categories and theoretical sampling to maximise similarities and differences of information (Creswell, 2009). Coding is a key part of GT and it forms a part of content analysis, whereby issues identified from data are conceptualised, but as identified in Table 2 (p.58) there are differences between Strauss & Corbin's approach and Glaser's view on this process (Heath & Cowley, 2004). Concepts are codes that are grouped together into themes following analysis.

Categories are formed when concepts are grouped and regrouped for more depth of detail. It is the evolution of codes and categories in this manner that leads to emergence of the theory (Ke & Wenglensky, 2010).

Glaser and Strauss both agreed on the approach to data analysis, but disparity occurred in the labelling or coding of the data from which categories are created. The relationships between the categories in GT are identified to determine core categories leading to the core concern. The coding phase for Glaser (1992) is called substantive coding and is data dependent, while Strauss terms his equivalent phase open coding followed by axial coding and selective coding using an analytic technique. Glaser (1992) argued that grounded theory is about the emergence of theory through data conceptualisation and that axial coding introduces preconceptions into analysis that are not compatible with the premise of grounded theory.

Strauss's difference of opinion was based on a more structured approach to data using constant comparative analysis resulting in a full conceptual description through the use of verification (of relationships between categories, of emerging theories). Strauss & Corbin maintained that the process of verification is part of the research process itself and espouse use of both deductive and inductive approaches. In contrast Glaser (1998) argued the need for a purely inductive approach and that GT is about abstraction and not the description advocated by Strauss and Corbin (1990). Table 2 below outlines the differences in approach:

Table 2: Strauss & Corbin versus Glaser (Heath & Cowley, 2004, p.146)

	Strauss &Corbin	Glaser
Initial coding	Open coding Use of analytic technique	Substantive coding Data dependent
Intermediate phase	Axial coding	Continuous with previous phase Comparisons with focus on data, become more abstract, categories refitted, emerging frameworks
Final development	Selective coding Detailed development of categories, selection of core, integration of categories	Theoretical Refitting and refinement of categories which integrate around emerging core
Theory	Detailed & dense process fully described	Parsimony, scope and modifiability

Strauss' version of GT was rejected for the purpose of the current study on the basis of the contention around coding and verification processes that could potentially undermine emergent theory.

Wuest (1995) introduced the notion of feminist grounded theory, she used reflexivity to ensure respect for both a feminist and grounded theory approach was maintained. This feminist approach was aimed at studies purely focused on female participants, which mine was not. Therefore, it was discounted as a choice for the current study.

Charmaz was a student of Glaser & Strauss and she has been pivotal in the introduction of constructivist grounded theory through her book *Constructing*

Grounded Theory (Charmaz, 2006). The constructivist grounded theory approach espoused by Charmaz (2006) is perceived by Glaser as yet another remodelling of GT to fit the needs of qualitative data analysis; losing the abstraction process he views as vital to emerging theory (Glaser, 2002).

In constructivist grounded theory there is more emphasis on the role the researcher plays in the process (co-producer); using reflexivity, finding meaning and using imagination. In Glaserian grounded theory (GGT) the strategy is to seek data, describe observed events, and answer fundamental questions about what is happening, and then develop theoretical categories to explain it through the theory that emerges (Holton, 2008). While the constructivist approach had potential to be used for the study, the researcher felt that GGT had the most potential to remain true to the participant data.

Whilst criticism of the Strauss & Corbin version suggested that differences in the methodological approach had potential to overpower what data had to say (Evans, 2013). Charmaz's (2000) constructivist version of GT faced criticism for being a prescriptive and directive approach over emphasising construction and losing abstraction (Simmons, 2011).

The theoretical basis of constructivist grounded theory is that the study is the vessel through which participants' experiences and meanings are interpreted to form grounded theories that reflect these imposed constructions of reality. The

researcher can see the merits of using constructivist grounded theory. However, Charmaz (2006) seems to have created a grounded theory approach with emphasis on applying multiple questions to data analysis and coding that could potentially sabotage the emergence of theory (Glaser, 2004).

Constructivist grounded theory was not perceived as the most appropriate manner to elicit the participant voice in this study and was therefore rejected. GGT retains the participant voice; thus was identified as the most appropriate version of grounded theory for this study, remaining as pure as possible to what the data have to say.

3.3.3 Why Glaserian grounded theory?

The researcher had some experience of phenomenology as a methodology, but had never considered GT. Phenomenology does not have to be descriptive and it can culminate in development of a theory, but requires use of additional frameworks to achieve this. It was feasible, but GGT was the most appropriate method to answer the research questions, aim and objectives posed in the current study as outlined on page 50 of this chapter. Selecting GGT was the right decision as it has reflected participant views and experiences remaining true to what they have said.

GGT has philosophical flexibility and is perceived as unbiased; therefore it is applicable to any study and type of data where the intent is to generate a conceptually generated theory (Holton & Walsh, 2016). A strength of grounded theory lies in the ability to move data from a descriptive to a conceptual level, but this

can be a confusing process (Artinian *et al.*, 2009). In grounded theory the researcher can benefit from knowing little about the subject being studied to having expert knowledge of the theory that emerges. The theory can be modified if new data indicate new categories or properties of categories.

The problems in grounded theory tend to originate from the researcher rather than the method. It is usually the researcher's preconceptions about participants' responses that can sabotage the process (Simmons, 2011). Another researcher based difficulty is the need to tell every detailed aspect of the story. It can be a challenge for the researcher to leave aspects behind that are not specific to the core category. Story telling like Charmaz' work (1999) is what Glaser describes as qualitative data analysis, but he does not construe it as grounded theory. Sample size cannot be predicted at the outset and relies instead on homogeneity of the sample and data saturation. Glaser does not advocate use of interview guides, but for novice researchers this may be a necessary part of the process. He argues that audio taping interviews create an information overload rather than capturing the main ideas (Artinian *et al.*, 2009).

3.3.4 GGT overview of process

Grounded theory is the systematic generation of theory through a systematic approach that follows rigorous research procedures that lead to the emergence of conceptual categories. The relationship between the conceptual categories forms a theoretical explanation of the actions that continually resolve the participants' core

concern in a substantive area (Glaser, 2012). In grounded theory, participants identify the research problem through their perception of what has been significant to them and telling the researcher how they manage that problem (Simmons, 2011).

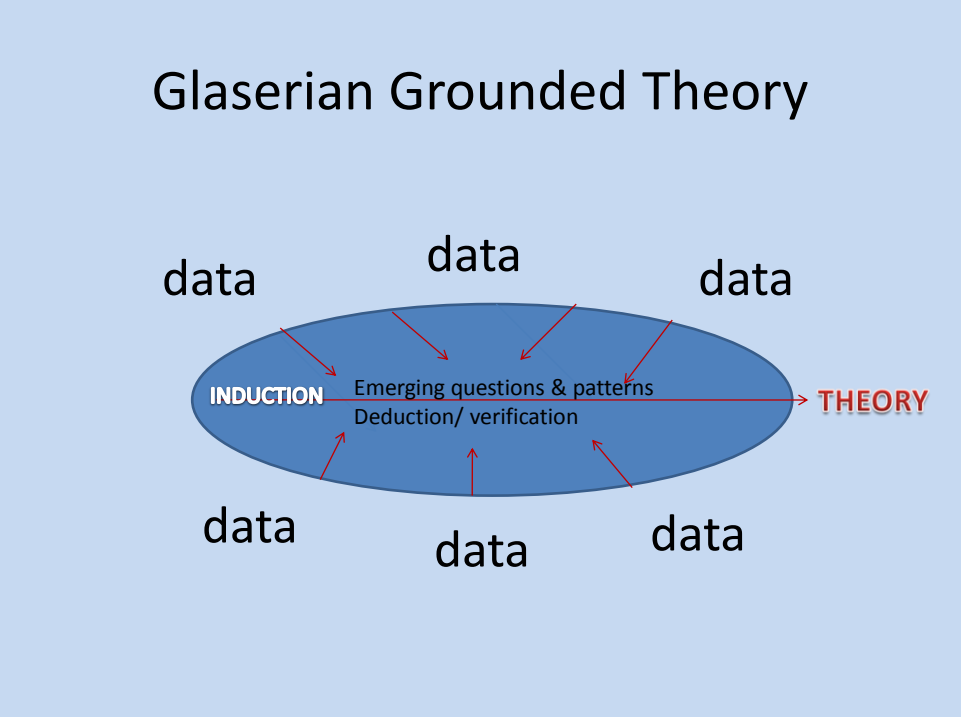
GGT method is about abstract conceptualisations with the key focus on the substantive area of inquiry in order to enable a true emerging theory to be generated (Glaser, 1998). The aim is that the researcher can answer questions that lead to understanding the complex processes that are occurring. It is seen as an appropriate way to study an area where little is currently known. In GGT the unit of analysis is not the person, but the incident. These incidents may be numerous in a GGT study. When comparing many incidents in a certain area, the emerging concepts and their relationships are in reality probability statements. So the results of GGT are a set of probability statements about the relationships between concepts, or an integrated set of conceptual hypotheses developed from empirical data (Glaser, 1998).

The researcher may have sensitising concepts, which are described as not having specific attributes, rather they provide a general sense of direction in which to work (Bowen, 2006).They capture issues of background interest, assumptions about the area of study, but a hypothesis is not tested in favour of detailed analysis facilitating the emergence of theory (Lingard *et al*., 2008). It has an iterative study design with cycles of simultaneous data collection and analysis. The analysis informs the next cycle of data collection, theoretical (purposive) sampling and system of analysis (Lingard *et al*., 2008). Glaser (2004) says to avoid descriptive interpretation and

instead use abstract conceptualisations using constant comparison, this in his view facilitates emergence of stable patterns in data/concepts.

Glaser has maintained induction as a key process in GGT, moving from data to empirical generalisation and developing theory (Bulmer, 1979). The role of induction, deduction and verification is outlined in Figure 2.

Figure 2: GGT process (1978, 1992) place of induction, deduction and verification in grounded theory analysis (Heath & Cowley, 2004 p.144)



Induction is seen as the fundamental process in developing theory (Glaser, 2011). As data are analysed and coded, ideas and potential insights are developed and recorded in theoretical memos (Evans, 2013). Imagination and creativity used in

memoing are vital to ensure development of a theory which captures and enhances knowledge and understanding of the substantive issue (Glaser, 2011). Deduction and verification are subservient to emergence, whereas Straussarian GT disagrees on this aspect of the process (Holton, 2008). Ideas generated must be verified by all data and categories are constantly refitted (Glaser, 1978) to ongoing comparisons of incidents in old and new data, being mindful of forcing data (Glaser, 1992).

The data inform theoretical sampling, which is the process of data collection for generating theory where the researcher jointly analyses data, creates codes and decides what data to collect next and where to find it, in order to develop a theory as it emerges (Glaser, 1978).

The relationship between the question that the researcher sets out to answer and the research design used to answer the question are pivotal to any study. It was important to ensure that an appropriate design was chosen to answer the question, because an inappropriate design leads to undermining of the quality of the study. The research question is dependent upon the purpose of the research, what the researcher wants to know, what is known already and what type of data will be generated. The following section explores the researchers' decision making regarding the design of the study in keeping with use of GGT.

3.4 Research design

A research design can be defined as a plan outlining how, when and where data are to be collected and analysed (Parahoo, 2014). The research design provides a framework for the collection and analysis of data and reflects the decisions made by the researcher regarding the tools chosen for these processes (Polit & Beck, 2008).

The following sections of this chapter explore the researcher's decisions regarding the research design.

3.4.1 The research setting

At the commencement of the study in 2010, there was only one critical care unit in Wales with a diary team and where patient diaries had been implemented. They wanted evidence to identify if investment in patient diaries was indicated, or not, as there was little research based evidence to support their use. The researcher had expressed an interest in doing a PhD and was invited to meet with the critical care team involved in diary use and that led to this study.

The critical care unit involved in this study is split between two distinct environments; these being the intensive care unit (ITU) and high dependency unit (HDU). ITU consists of twelve beds and two side rooms; while HDU has six beds and one side room. Internal rotation of staff between the two environments is practised.

The critical care unit covers a large geographical area and is based in a district general hospital. Patients require referral and transfer should their treatment require more complex interventions that can only be provided in the regional specialist hospital.

3.4.2 Participants and recruitment

Once ethical approval processes were complete and the study could begin, a meeting was held between the researcher and diary team to discuss the recruitment process: referral to the study inclusion and exclusion criteria, contents of the study information packs and to answer any questions they had. One hundred ready-made study information packs were provided for the diary team to address and send alongside the diary invitation to patients who they were inviting to collect their diary. Their practice was to send the invitation at six weeks after patients had been discharged to their home. The diary team tracked patients through the healthcare system to identify this information and also to identify any deaths and avoid sending information to bereaved families. Study packs included information about the study, contact details and Freepost envelopes if people wished to participate.

In hindsight the researcher should have been at the forefront of the recruitment process and considered alternative strategies to aid in the process; such as adding the personal touch of face to face explanation of the study and seeking to recruit in a more personal manner than was actually implemented. Study packs could have been construed as too onerous to read so soon after post-ICU discharge.

All participants were admitted to the critical care unit at the study site and met the study inclusion/exclusion criteria (see Table 3 below).

Table 3: Study inclusion/exclusion criteria

Inclusion criteria:
Adults age 18 years or above
Critical Care Survivors
≥48 hours intubated and ventilated
Patients who are capable of providing informed consent to participate.
Exclusion criteria:
Patients who are unable to provide consent to participate.
Patients who remain too unwell to participate.

Most participants were approached to take part in the study by postal invitation. However, some were also recruited while attending the appointment to collect their diary. The diary team prompted them about the study information packs and asked if they wanted to participate in the study. In hindsight, this meant sampling would have favoured a sample representative of those patients who did want their diary. Furthermore, the fact that some participants were attending an appointment to collect their diary may have influenced their willingness to participate in the study.

A total of fifty nine participant information packs were distributed with ten returned. The researcher was not aware at the time that her main link in the diary team for recruitment had changed jobs and it is possible that key information was not handed

over about the study inclusion/exclusion criteria. It was clear that the inclusion/ exclusion criteria may apply on face value when looking at patient notes, but there was the reality that recovery from critical illness, once home, could lead to a participant not actually being well enough to take part.

3.4.3 Sample

Sampling was purposive (selection against pre-determined criteria i.e.: the inclusion/exclusion criteria above). The benefit of purposive sampling is the ability to gain in-depth information about the area of interest directly from those who have experienced it (Polit & Beck, 2008). The aim was for the sample to provide a purposive selection of patients who had been critically ill and had a diary written on their behalf, with the intention of capturing participants who did, and did not, want to collect their diary (Guest *et al*., 2006). The researcher had anticipated recruiting participants who wanted to collect their diary, as well as those who did not. In reality this strategy was limited with only one participant was recruited who had no intention of collecting his diary. One participant (Participant 8, Harry) was suffering ill health and the researcher felt it inappropriate to interview him on a third occasion. This was discussed at the end of his second interview and he seemed comfortable with that decision. The researcher was concerned that the participant (participant 9- no pseudonym given), who withdrew, did not meet the study inclusion criteria and was going to meet him to assess the situation as she felt he was sent the study pack erroneously. Therefore, it was not possible in the remit of this study to establish perceptions of patients who did, and did not, want their diary.

A sample size of *n*=10 participants was recruited for this study, with one withdrawal prior to their first interview. The actual sample consisted of six women and three men *n*=9. This was a small sample size, but that is acceptable within qualitative in-depth studies (Francis *et al.,* 2010). Using a qualitative paradigm within a grounded theory means numbers recruited will be small. In qualitative ontology small numbers of participants enable the researcher to explore experiences in more detail (Polit & Beck, 2012).

There is a gender imbalance in the sample with more women represented than men. The concern with this is whether the sample is truly representative of the population being studied and perhaps as described above a different recruitment strategy should have been employed. However, despite the gender imbalance all participants provided similar perceptions and data saturation was reached where no new information was forthcoming. It could be argued that had recruitment altered to capture participants who did not want their diary that may have introduced information pertaining to why some patients preferred not to collect their diary and an opportunity to compare these different viewpoints was lost. Another consideration was that if there had been equal representation of gender that may have led to further insight. It is important to note that no sample strategy will be perfect (Holland & Rees, 2010).

3.4.4 Patient demographic data

The diary team were asked to complete a participant demographic data collection sheet providing brief background details such as date of admission to determine length of stay, reason for admission, length of time in critical care and in hospital overall, gender and age. It was anticipated that socio-demographic data would be useful in identifying potential trends in patient demographics that could have impacted on participant perceptions of diary use, or their experiences, during recovery from critical illness. However, more often than not these forms were not completed due to clinical workload pressures. The researcher was able to use regular contact meetings with the diary team to complete any missing information and clarify with participants, but the information proved useful only for background context.

Table 4, p.71 below outlines the participants, their pseudonym and dates of the three phases of interviews. It also identifies, in brackets, if the interview was conducted alone or with the significant other present. In some participant interviews having the significant other was helpful as they were able to prompt discussion, particularly when participants could not remember certain aspects. Some significant others needed to tell their story of events before handing over to the participant to carry on the interview.

Table 4: Participant data

Participant & pseudonym	Reason for admission	Length of stay in ICU	Length of hospital admission	Interviews
1 Alice *(recruited prior to diary collection)*	Respiratory, Gastrointestinal & sepsis	1 week	2 months	27/12/11(alone) 29/03/12(husband) 22/10/12(alone)
2 Beth *(had diary)*	Respiratory, Cardiac, neurological	10 days	2 weeks	01/02/12(husband) 14/05/12(husband) 12/10/12(husband)
3 Clara *(recruited prior to diary collection)*	Sepsis and Cardiac Surgery	1 month	4 months	08/02/12(husband) 11/06/12(husband) 19/10/12(husband)
4 Diane *(had diary)*	Respiratory and renal	1 week	1 month	23/02/12(alone) 20/06/12(alone) 16/10/12(alone)
5 Emily *(had diary)*	Respiratory and sepsis	5 days + 2 days	7 days + 10 days	06/03/12(alone) 27/06/12(alone) 04/12/12(alone)
6 Fran *(had diary)*	Neurological	5 days	2 months	02/05/12(husband) 17/10/12(alone) 11/02/13(alone)
7 Graham *(recruited prior to diary collection)*	Sepsis & Cardiac Surgery	6 weeks	2 months	15/06/12(wife) 16/10/12(wife) 31/01/13(wife)
8 Harry *(recruited prior to diary collection)*	Gastrointestinal and sepsis	2 weeks	1 month	02/07/12(alone) 15/10/12(alone) Ill health
9 Male	Withdrew from study			
10 Ian *(had diary)*	Gastrointestinal and sepsis	2 weeks	6 months	12/11/12(wife) 28/02/13(alone) 12/06/13(alone)

The age of participants ranged from 40-73 with a mean age of 58.4 years. Length of stay in critical care and hospital overall varied, with some spending one week to the longest stay of six weeks in critical care. The majority spent two months or longer in

hospital as a result of their critical illness. One participant was unfortunate enough to have two admissions to critical care as a result of the same condition (participant 5, Emily). Two participants were transferred to a specialist hospital for further treatment (participant 3, Clara and participant 7, Graham). One participant, (Participant 10, Ian), had a complex critical illness trajectory and whilst only spending two weeks in critical care he required six months recovering in the hospital prior to discharge home.

3.4.5 Data collection

In a pure GGT approach unstructured interviews are used by choice, but as a novice researcher, unequipped with the necessary knowledge and skills, semi-structured interview guides were used (see Appendix 2, p.385). A longitudinal qualitative design using Serial Qualitative Interviews (SQIs) enabled the data collected for analysis to be reflective of what was actually happening to participants in relation to diary use, experiences since discharge home and recovery over a period of a year post critical illness (Kvale & Brinkmann, 2009).

In GGT the sample were interviewed sequentially at two, six and twelve months in an overlapping process of constant comparative analysis where interviews were used to inform the next and were transcribed and analysed simultaneously. The longitudinal approach was beneficial in that it facilitated insight into critical care survivor's recovery process over the period of a year; capturing the most significant period of recovery (Rattray, 2013).

There are various interview techniques that can be utilised for research purposes, such as, formal interviews that include structured, semi-structured and unstructured interviews. In order to ensure this study was representative of other longitudinal qualitative research studies using a twelve month timescale; the researcher chose to use interviews, which were sequential to facilitate a longitudinal approach at two, six and twelve months post-ICU discharge (Löf *et al.,* 2006, 2008, Agård *et al.,* 2012). In longitudinal qualitative research using Serial Qualitative Interviews (SQIs) the timing of recruitment is important to capture perceptions of the area of study at the most useful time points (Murray *et al.*, 2009).

Murray *et al*. (2009) propose that longitudinal qualitative research enables researchers to gain greater insight into the participants' individual and changing experiences of their illness than would ordinarily occur from a one off interview. They highlight that SQIs facilitate a participant and researcher relationship that can enable participants to be more open about sensitive or emotive personal concerns related to their illness, care or recovery.

The selection of two months for the initial interview gave time for potential participants to have been discharged from hospital and to have received the invitation to collect their diary and study information. Interview at six months would reflect the midpoint of the recovery period being studied and aim to capture any changes in perceptions, interaction with their diary and aspects of recovery that the

participants felt significant to share. The last interview at twelve months was an opportunity to further explore and clarify key issues identified from data and to ascertain patterns in participant perceptions of their recovery and the role their diary may have played.

Using SQIs offered the added benefit of establishing a rapport between the researcher and participants. However, the researcher had to be mindful of her role and purpose in the interview process; meaning it was not about counselling or health advice (Murray *et al*., 2009). It is important that a suitable environment (such as a room away from the critical care area or at the participant's home), time and place are organised at the participant's convenience for data collection (Robinson, 2006, Mapp, 2008). In the case of this study, all participants chose to be interviewed in their own homes.

According to Murray *et al*. (2009) the qualitative interview may be the only opportunity the participants get to tell their story and this can be empowering for them. In SQI's a relationship can develop whereby they are more open in their disclosure of thoughts and feelings about their experience.

The participants and significant others said that they found the interviews clarified things and helped their mutual understanding. They had found the process useful in terms of it allowing them to tell their stories and some expressed concern that had they not taken part in the study, there would have been no opportunity for them to be

listened to or followed up after their critical illness experience. SQIs took place between 27th December 2011 and the final interview was conducted on 12th June 2013, therefore taking just over 18 months to complete the three phases of data collection.

According to Holland *et al*. (2006) data overload is a risk for the researcher, especially when interview phases overlap. A concern about using this approach is the enormous amount of data that the researcher has to contend with and organisation and planning are seen as essential (Kvale & Brinkmann, 2009). Field notes were used to aid in capturing emotions, behaviour and key points that may otherwise have been lost.

Table 5 below outlines the amount of data collected for each interview phase during the current study.

Table 5: Amount of data collected for each interview phase

Amount of data collected for each interview phase		
2 months	6 months	12months
829 mins= 13.8 hours	675 mins=11.25 hours	436 mins= 7.26 hours
	Total amount of data from this study	**1,940 mins= 32.30 hours**

According to Murray *et al*. (2009) the qualitative interview may be the only opportunity the participants get to tell their story and this can be empowering for them. In SQI's a relationship can develop whereby they are more open in their disclosure of thoughts and feelings about their experience.

The researcher noticed that when something significant had occurred, participants would refer back to it at each interview. Over time their views sometimes altered from a negative to a positive stance and having a significant other present at interview had helped some participants and their families to have a greater understanding of each other's perspective. Some expressed how they talked about events, but did not really think about some of the concerns each had raised during the interview conversation. This had proven to be helpful to the dynamics of the couple in the post-ICU recovery period. Conducting the research with these participants, willingly sharing such intimate and significant experiences was a privilege.

Theoretical sampling is described as data collection for generating theory and requires the researcher to jointly code and analyse data to adjust subsequent data collection in order to develop theory as it emerges (Evans, 2013). Ultimately theoretical sampling helped the researcher prioritise the questions asked of participants. Interview questions were also adjusted by using theoretical sensitivity, which forms from accessing literature pertinent to the themes emerging from the interviews (Glaser, 1978). Once no new data were evident during interviews the researcher felt data saturation had been achieved and data collection stopped (Holloway & Norton, 2010). This was confirmed when data analysis was complete and theoretical saturation was evident in the data and no further data collection was required (Simmons, 2011).

All interviews were conducted during the daylight hours. The researcher abided by the university lone working policy; ensuring that her whereabouts during the interview phases were known to one university appointed individual and contact was made on both entry and exit from the interview.

3.4.6 Data analysis

The goal in GGT is not description, but generating concepts that explain people's actions, regardless of time and place. Description is only used to explain the concepts. In GT the unit of analysis is not the person, but the incident. These incidents may be numerous in a GT study. The findings of GGT are a set of probability statements about the relationships between concepts, or an integrated set of conceptual hypotheses developed from empirical data (Glaser, 1998). Therefore, analysis and data inform each other continuously and constant comparative analysis was carried out between each interview conducted in this study to facilitate emerging working propositions and grounded theory (Glaser, 1998, 2011).

GGT consists of the following stages of data analysis:

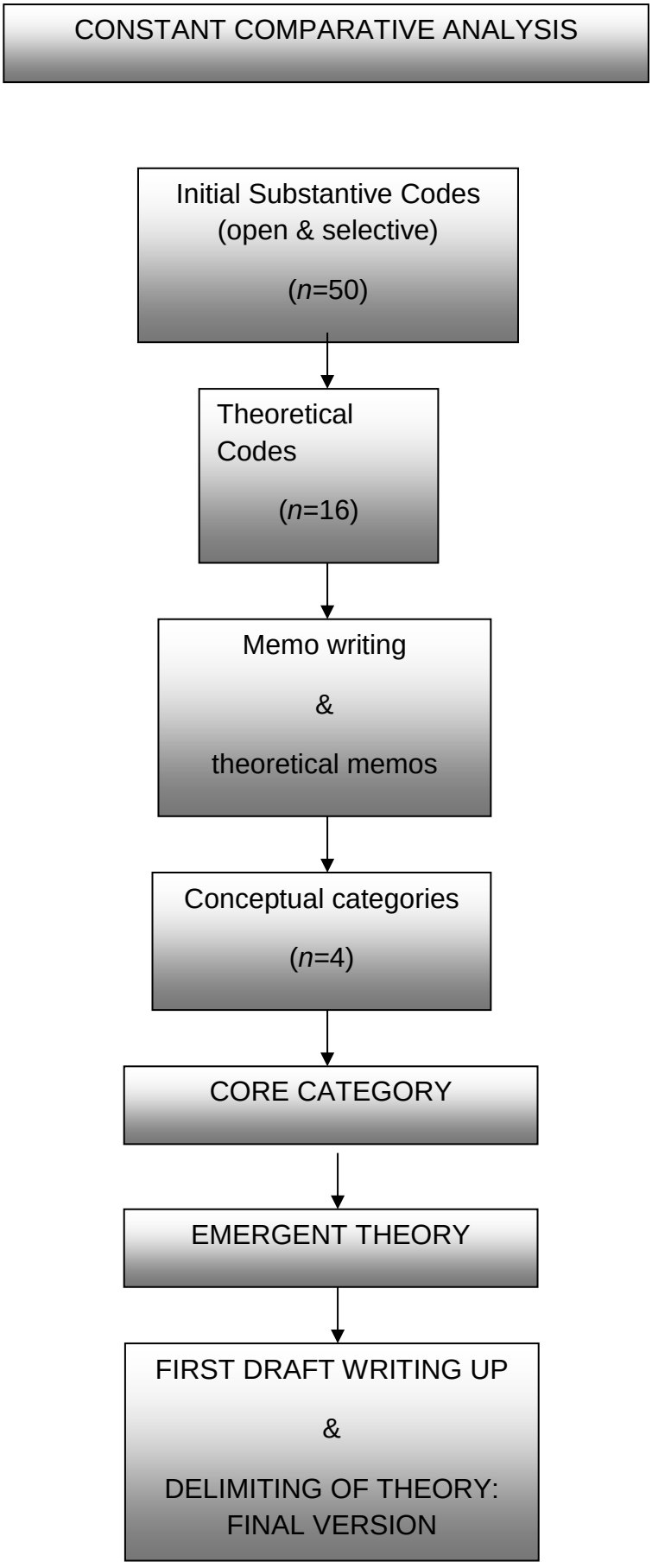
1. Initial coding, which is substantive and data dependent
2. Intermediate phase, continuation of above with constant comparative analysis.
3. Constant comparative analysis itself has four stages (Glaser, 2008):
    - Comparing incidents applicable to each category
    - Integrating categories and their properties

- Delimiting the theory
- Writing the theory

4. Emerging theory synchronised with the above processes through theoretical development, refitting and refining of categories which integrate around a core concern. The theory should have scope and modifiability
   (Adapted from Heath & Cowley, 2004, p.146).

Figure 3, p.79 below outlines the connecting processes required for conducting GGT. Although displayed as a flowchart, in reality the processes overlap. The processes in the flowchart are explored in this section of the chapter.

Figure 3: data analysis



Constant comparative analysis is central to GT, it is a complex process that leads to the redesigning of the research as new concepts emerge and relationships amongst the variables develop. The incidents in the data lead to concepts that become categories. Incidences related to categories are then compared allowing the formation of the properties of categories. Categories are subsequently compared with each other and refined until no new information is identified, thus saturation has occurred and no further categories arise and old categories no longer expand (Glaser & Strauss, 1967).

Constant comparative analysis is about generating accurate evidence about the area of study. Generalisations are made and explored to generate new theory which captures the maximum behavioural variation from participants (Holton, 2008, Simmons, 2011, Stern & Porr, 2011).

3.4.6.1 Transcription and use of NVivo

The initial analysis of transcripts and field notes should begin immediately with subsequent SQIs continuing to generate data, thus enabling emerging themes and concepts to be tested and developed in subsequent interviews (Murray *et al*., 2009). The researcher completed her own transcribing, which she felt aided the coding process and development of concepts.

It is advocated that interviews should last between 60 – 90 minutes and that they are transcribed verbatim (Lundqvist *et al.,* 2002). Table 6 below outlines the average interview length in relation to each phase of SQI. It is interesting to note that the

initial interview was the longest, but this fits with establishing the participants' stories and responses to initial questions. At six and twelve months the interview length decreases as these interviews were aimed at clarifying previous data and exploring new codes and categories that had emerged from the data. This is demonstrated in Table 6 below.

Table 6: the average length of interview for the three phases of SQI's

Average length of interview		
2 months	6 months	12months
92 mins=1.53 hours	75mins= 1.25 hours	54.5 mins

The interviews were transcribed verbatim in English and anonymity was maintained. This was done by anonymising participants' identity, initially using numbers and eventually applying pseudonyms. The transcripts were saved in NVivo 10 and backed up on the hard drive on the researchers password protected computer in a locked office. By listening to and replaying interviews the researcher was able to clarify what was said and to make note of emotional responses. Field notes added context of behaviour and body language at certain points in the interviews. Transcription was done in full for every interview and the researcher found it useful to print transcripts, maintaining confidentiality and anonymity, so they could be read and re-read. It was useful to write memos in the margins and to highlight key words or points of interest.

As transcription progressed the researcher was able to make memos about codes and concepts and connections began to emerge as part of the constant comparative

analysis between each interview. NVivo 10 helped the researcher to establish relationships between data and to form codes in order to manage the large amount of data.

There are pros and cons to using computer software or manual handling of data in the management of qualitative data. Computer Assisted Qualitative Analysis Software (CAQDAS) like NVivo 10 is compatible for use of grounded theory; the nodes facilitate formation of a coding structure and development of conceptual categories. This is possible through a manual approach with the researcher using a paper trail to develop the process rather than a database system. The amount of data to be handled can be overwhelming if done manually and using a system like NVivo 10 centralises the study paperwork and removes some of the anxiety around locating specific information (Zamawe, 2015). Manual analysis can be complex with colour coding, cutting and pasting or using post it notes, securing the information is not as easy as if it is done electronically (Burnard & Davis, 2006).

Using NVivo 10 and documents of the transcripts in a combined manner worked well for the researcher and essentially provided an audit trail of the development and progress of the study (available on request).

3.4.6.2 The coding process followed

The main concepts in grounded theory are codes, coding and development of categories. Data are collected and from this data key points are identified as codes:

the codes are grouped to form concepts which become categories that inform the generation of theory or hypothesis (Glaser, 2011, 2012). The process of identifying, refining and integrating categories leading to the emerging theory requires the use of strategies or key features, such as constant comparative analysis, theoretical sampling and theoretical coding (Lingard *et al*., 2008).

All interviews were analysed individually and compared with those conducted previously, as expected with constant comparative analysis. Coding required reading transcripts line by line, to identify key words, phrases or incidents. Over time new codes became less likely and there were clear patterns emerging in the data.

Using NVivo 10 and discussion with one of the supervisors, an initial coding framework was agreed (see Table 7 below). As a novice researcher this was necessary to clarify the process.

Table 7: Initial coding framework

Initial coding framework emerged from NVivo 10
Attitudes
Autonomy
Background data
Come to terms (in-vivo code)
Communication
Control
Critical care
Dignity
Feelings
Family
Illness story
Lost days/time/ out of it
Making sense
Memory
Mortality
Perceptions of care
Recovery
Diary

The codes identified eventually linked to form categories or key themes that encircled the core category (concern/variable). Writing the findings chapters and first draft of the thesis, encompassing memos, enabled the researcher to develop a more detailed theoretical view of the study.

Glaserian grounded theory (GGT) uses two forms of codes: substantive and theoretical as outlined below:

Open coding is about the researcher searching in order to code anything and everything; using an overview and microscopic level of insight and developing categories which inform theoretical coding (Denscombe, 2003, Grix, 2004). Initially

coding is a busy process which slows as patterns emerge. Open coding continues until data forms a set of categories which are relevant to theory integration (Glaser, 2003). Substantive coding entails open coding followed by selective coding aiming to conceptualise the empirical substance of the area being studied.

The table below outlines the resulting substantive coding produced through constant comparative analysis of the data.

Table 8: Substantive coding

Critical care experience
“Being out of it”
Memory
“Is it normal to feel like this?”
“Lost days”
“Lost time”
Existence
“Surreal” versus “reality”
Dreams
Hallucinations
Nightmares
Waking
Information, communication & explanation
“Making sense”
Being ready to know
Behaviour
“Shock”
Avoidance
“Mentally what a patient has to go through”
“Try to understand”
“Need to know”
“Filling in”
Family support
Consequences
“Realise how ill I was”
“Setback”
Facing own mortality
“Coming to terms”
Leaving critical care
“Reality of coming home”
Family experience
Family “tougher time”
Family “coming to terms”

Diary process
Collecting the diary
Staff as strangers
Seeing critical care
Narrative content: diary entries
Photographs
Perceptions of care
Diary Expectations
Diary limitations
The diary role
Recovery & progress
Anniversary
Moving on
Gratitude & appreciation
Security

According to Glaser (2013a) theoretical codes (TC's) are emerging abstract models from mature memos that result in a potential substantive theory. They are conceptualisations of substantive codes that create hypotheses towards theory development. According to Glaser substantive coding comes easier than theoretical coding and hence he says they tend to be implicit (range, dimensions or process) rather than explicit in writing up of grounded theory because the novice GT researcher struggles to represent them in their theory. TCs essentially are abstract models that integrate categories and their properties forming a theory. A TC needs to integrate the substantive codes in such a way that their fit and relevance is explicit in the theory (Glaser, 2013b). Substantive codes are essential to TCs and the most common TC represents dimensions of a core concept. The integrative interactions between substantive and TCs are what substantiate generation of GT. A core category may be a TC that has been named.

In this study theoretical memos, which are discussed later, helped form the theoretical coding and the relationship of these themes to conceptual categories.

The conceptual categories are depicted in bold above the associated codes that inform the theory is outlined in Table 9. These are explored in Chapters 4-7 and Chapter 8:

Table 9: Theoretical development from codes to formation of conceptual categories and subthemes that developed into the ensuing chapters

CODING	**CONCEPTUAL CATEGORIES (Bold)** and associated codes
Critical care, "out of it"	**"Being out of it"**
"Lost days", "lost time", "exist"	"lost days"
Memory, dreams, hallucinations, "surreal", "reality"	Memory loss
"control"	Loss of control
"Existence"	Existential crisis and self-identity
	Recovery: "Is it normal to feel like this?"
Mentally, shock, life threatening	"Mentally what a patient has to go through"
Understand, appreciate how ill, not knowing, journey	"Realise how ill I was"; "anniversary"
Recovery, progress, setbacks, limitations	Recovery & progress: "the struggle"
	"Something I must know"
Not knowing, understanding, explain, Worry, panic, scared	Communication
"Family support" once home, "emotional", "dependent", "not telling me everything", "families go through it more than you", "stressful"	Family role
"unable to move", "weak", "shock", "stay strong", "explanation", "out of my control", care and attention, "coming to terms", "accepted it", "questions", "answers", "confidence", experiences," trapped", flashbacks, stronger	Uncertainty, "regaining confidence" and "coming to terms"
"shock", "limitations", "realise", "accept"	"Regaining confidence"; "coming to terms"
	"It's a piece of jigsaw"
Process- participant perceptions, angry, expectations	The diary process
"harsh realities", "go down that road"	"Being ready to know"
"Jigsaw", "limitations", "story", "journey"	Capturing what happened
Needing to know what happened, Family control of information, feelings, reading it, care, nurses contribution, personal to them, reassure, peace of mind, control, comfort, chronological, missing dates, black hole	Constructing the critical illness story
Follow-up, aftercare, confrontational, coping, questions unanswered, emotive, unsupported process.	Benefit versus harm

“Reassuring”, “personal”, “comfort”, “peace of mind”, “make sense”, “answers”, “journey”, “story”, “jigsaw”, “lost days”	Diary role

3.4.6.3 Memos

Memoing and capturing of ideas are essential to the actual write up of what emerges from data, its analysis, and theory generation. The researcher is required to theorise in their write up of ideas about codes and their relationships with no concern for grammar to minimise risk of writer’s block (Glaser, 2004). The premise is that memos can be modified as more data has impact and the ideas develop (Glaser, 2013b). Once theory is concrete enough, literature related to what the researcher is finding in the data is then analysed and integrated if relevant. Memos form a means of tracking the development of GT from the starting point of substantive to theoretical coding and finally to theory development (Glaser, 2013b). The memos identified in Table 10 below demonstrate how notes were made alongside participant quotes to help in the coding process (see Appendix 3, p.386 for further examples).

Table 10: example of memos from the current study

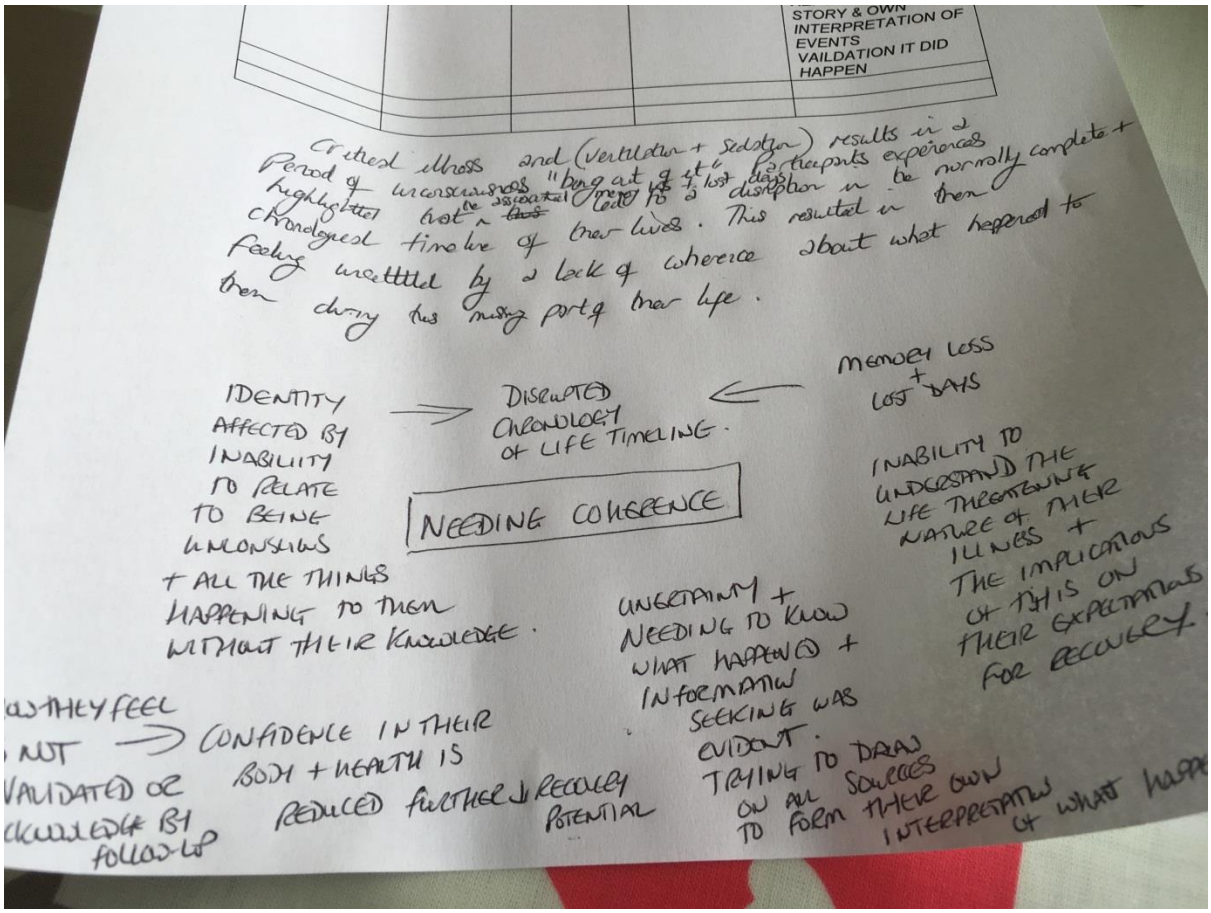
Memos
Evolves into potential detachment from the situation! Consider this more. Loss of control over all this as no memory consider this.
“My family talks to me obviously, but **they tell me** what’s happened” (Alice 2 months)
Family as a resource for information about what happened
“Which upset them obviously, more than me, cos they could see I was in pain, which I wasn’t feeling” (Alice 2 months)
Family going through more than the patient?
In vivo code: “**come to terms with”** or alter to **coming to terms with**

“It’s something I must know” (Alice 2 months): Knowing what happened is important, seems to be relying on family as a source of information, but possibly feels this is not enough: ‘something **I got to know**.’

Memos are modified and refined as the research develops and Glaser advocates memo development is kept in chronological order (Glaser, 2012). Theoretical memos are a means of unlocking connections between ‘conscious, unconscious and preconscious mind’ (Glaser, 2013b). Something considered early on may not seem significant, but in final sorting of memos the researcher finds relevance.

The researcher used hand written memos and digital voice recorded memos to work through ideas and eventually develop theoretical memos. The example in Figure 4 below outlines how developing concepts were mapped with ideas to help them evolve into categories.

Figure 4: Example theoretical memo from the current study



Listening back to recorded memos enabled clarification of thoughts and informed written memos so they could evolve theoretically as required in GGT. Without this process key concepts could have been missed or lost. Memo development benefited from the researcher transcribing the data herself. As confidence increased and the data grew, some coding and memoing was able to be integrated during transcription, using bold or different colour coding where data were of interest.

3.5 Ethical considerations

The experience of being critically ill often means the patient has come close to dying and therefore it is an emotive and confrontational topic to study. The research needs to be carried out sensitively and compassionately from start to finish for each participant (Lowes & Gill, 2006). The researcher needed to carefully consider the potential ethical issues that could occur within this study both for the novice researcher and each participant who agreed to take part. Discussion with the supervision team and other experienced research colleagues enabled the researcher to identify and consider the key ethical concerns pertaining to the study.

The researcher also attended the Good Clinical Practice Training for researchers, this raised awareness of ethical issues (28/03/2011). These issues incorporated informed consent, discussing emotive or sensitive topics and maintaining confidentiality as espoused when dealing with human beings. The study site Health Board research risk review was approved on 6th May 2011 and Health Board Research and Development research scrutiny was approved on 11th May 2011 (see Appendix 4, p.391). Ethical approval for the study was sought from the University Faculty Ethics Board and was approved on 25th July 2011. On 20th September 2011 the study gained favourable opinion from South East Wales Research Ethics Committee for the National Research Ethics Service (NRES), providing independent scrutiny (see Appendix 5, p.394). Thus the necessary research approval was gained prior to commencing the study.

3.5.1 Consent

A challenge associated with this longitudinal research design was continued access to the participants for the period of the study (Steinhauser *et al.*, 2004). The consent form included the need to meet on three occasions during the study, but equally allowed participants to withdraw at any time they wished without detriment, but with consent to use data collected to that point. Steinhauser *et al.* (2004) highlight that establishing a good researcher and participant relationship at the outset reduces attrition. Generally participants that engage in the study will try to see it through; death or deterioration of illness is usually the cause of attrition in these cases.

Participants received the study information pack (see Appendix 6, p.396) The information was intended to fully inform participants of the purpose of the study and requirements associated with participation, so that they could make an informed decision to take part or not (Holland & Rees, 2010).

If the individual wanted to participate, a mutually agreeable date and venue were decided for the interviews. All participants wanted to be interviewed in their own home. Participants were asked to participate in three agreed scheduled interviews with consideration given to their length to avoid overburdening the participant (Murray *et al*., 2009).

Most participants had read the study information pack prior to the first interview and seemed enthusiastic about taking part. There were just a few who benefited from

going through the information and who clearly had not read the documents. It was vital for clarification about the study and informed consent to ensure all participants understood the study. The researcher went through the study information pack with each participant prior to obtaining their written consent (signed and dated) and re-affirmed this prior to each interview (see Appendix 7, p.401).

The researcher sought participants' permission to digitally record their interviews and explained why. She reiterated the purpose of the study and the information included in the study information pack, confirmed written and verbal consent for her records and clarified contact details. Continued consent to participate in the study was checked prior to each subsequent interview.

3.5.2 The harm versus benefit ratio

The researcher needs to ensure that the benefit derived from the study outweighs the amount of risk. A study is deemed ethical if there is a favourable risk-benefit ratio (Ioannidis *et al.,* 2004). It was essential consideration was given to ensure participants' safety, minimising harm, maintaining dignity and respect, well-being and the integrity of the research, the researcher role and responsibilities, throughout the study. A crucial step in this process was ensuring participants knew exactly what the study was about and what participation would entail.

The well-being of the participants in this study was paramount. The initial interview occurred at an early point in their recovery and it was important not to add any pressure. Qualitative interviews can be emotive when asking a patient to recall

experiences related to illness. However, for participants, talking about emotive experiences can be cathartic (Lowes & Gill, 2006). Prior to commencing the interview the participants were advised that they could pause, stop or withdraw from the interview at any point without detriment. Interestingly, feedback from participants was that if they cried, often they commented that it was the first time they had showed that emotion since it happened and they had needed to be strong for their family, or it just had not hit them until they started talking about it openly.

Before starting the interview the researcher tried to engage the participant in general conversation to try to alleviate their anxiety and to start to develop a rapport. The researcher tried to demonstrate that she was genuine, interested and professional, but approachable. When a participant became tearful the researcher was attentive and empathic, providing reassurance. It was important to acknowledge how they may be feeling and to give them time to work through it. No participants experienced lengthy episodes of emotion. When it did occur the researcher checked if they felt able to continue or if they wished to stop.

It was important to allow participants time to express their emotions and at the end of the interview to ensure they had composed themselves again by engaging in general conversation rather than discussing their critical illness experience. Most participants were not alone during the interviews and this offered them family support when the researcher left. There were no occasions when the researcher felt unable to leave because the participant was in a distressed state.

However, the researcher was aware that participants could experience a delayed emotional response. All participants were reminded after each interview that if they needed support they could access this through their General Practitioner (GP) or use the support links supplied with the study information pack. Prior to commencing the study the researcher met with the Health Board Clinical Psychology team who agreed to provide a consultancy role should any concern regarding participants' psychological well-being arise during interviews.

The aim was to safeguard the participant in terms of appropriate and prompt referral if the circumstance arose. Fortunately, none of the participants required referral for support either via counselling and most were in regular contact with their General Practitioner (GP). One participant had two interviews before alerting the researcher to health concerns that were being dealt with by the GP; this resulted in the decision that it would be inappropriate to interview for a third time. Some support service details that participants might find useful were attached to the participant information sheet included with the study information pack.

The benefits of participation were not overplayed and participants were made aware that their views might inform the future direction and development of diaries in critical care or follow- up provision post -ICU discharge.

3.5.3 Anonymity and confidentiality

It was vitally important to maintain anonymity and confidentiality of participants throughout this study. All participants were given a participant number initially, which was changed to a pseudonym for writing up purposes in order to relate to them as people. Participants consented to use of anonymous direct quotations for the purposes of sharing their stories, teaching and education.

All data collected; (transcripts, field notes and any other documents associated with the study) were managed and stored securely using the university NVivo 10 software programme or PhD folder stored on the hard drive of the researcher's work based computer. The computer was password protected, used only by the researcher and was stored in a locked office. Paper copies of transcripts, chapters, as examples, were anonymous and stored in a locked cupboard in a locked office. On completion of the study all information will be moved into the university archive storage facility and stored for five years, at which point it will be disposed of securely.

The researcher had a printed and bound version of interview phase one, two and three, and eventually a combined version of all interviews. This approach helped the researcher to explore data and maintain memo records. These resources were never left unattended and when not used were locked in a cupboard in a locked office.

3.6 Reflexivity

Conducting this research has been a journey for me both personally and as a researcher. It is not just a process that you follow, it requires you to engage, often intensely, and you need to adapt, learn and grow within the process. This has been challenging at times, but also rewarding. The challenges have been developing and sustaining a team approach while working closely with the diary team and maintaining effective communication throughout the five years it has taken. I also needed to develop my confidence in conducting research, through the recruitment process, interviews and analysis using Glaserian Grounded Theory.

I explored methodologies that were appropriate for the research question. In effect it was a decision between phenomenology or grounded theory. I explored both in detail and both were eligible approaches. I felt more affinity with grounded theory, specifically the Glaserian version because of its ability to focus on the patient voice through the data. I am an organised person and like a sense of control over what I do. So it was a major challenge for me when using GGT as it is very intense with all aspects occurring at the same time in continuous cycles of data collection, transcribing and analysis. My ability to be organised was useful, but the loss of control I had over key elements of the research, such as participants and the interviews, was difficult to adapt too initially.

The research journey has not been an easy one. I have had positive moments and negative moments, which is normal in such a long process. Using GGT has been challenging, but it is an approach that you continue to develop and understand

during your research career. I will certainly use it again, but with more confidence in the process through my research experience in conducting the current study.

I feel that despite trying to be organised and efficient, nothing can prepare you for the reality of being responsible for conducting a study and the intensity of the processes involved in interviewing, analysing and crafting the work. I feel I have been through an enormous, but rewarding learning process. I acknowledge that sometimes it was difficult to comprehend the data analysis and adhering to GT processes was fraught with hurdles. The literature says that GT is something that you learn to do better each time you use it. I think once you have experienced the pitfalls that occur you are better able to avoid them in subsequent research.

In hindsight I appreciate that I lacked confidence in the interview process and this did impact on my ability to maintain focus on participants' perceptions of their diary. I can now see that in allowing participants to tell me their story, then picking up and exploring the relevant points raised, and asking focused questions at the end was a mistake. This served to create more data that was about their critical care experience as well as the focus on the diary. If I were to do it again I would be confident about using the interview guide properly.

I had the support of my supervisors throughout the research journey and attended monthly supervision sessions. Counselling or debriefing after interviewing is recommended as it is seen as an emotionally charged process, especially when

using serial qualitative interviews (SQIs). Support was available to me and was accessed.

So for me, conducting this research has been a journey about knowing myself as much as it has been about developing my knowledge of research. My experience made me respectful of participants' stories and their need to be heard and acknowledged.

3.7 Achieving academic rigour

The rigour and quality of studies using qualitative methodologies which include ethnography, phenomenology and grounded theory, as examples, have been subject to debate. Therefore the robustness of the study findings are expected to be effectively evaluated. As previously stated, scientific research held prominence for many years leading to an assumption that quantitative evaluation criteria of internal and external validity, reliability and generalisability were transferable measurement tools for assessing the rigour and quality of qualitative research.

There are contentions that arise in the literature regarding how individuals can determine whether the qualitative research produced is worthy research, or not (Mason, 2010). The quality and standard of the study should emanate from the way in which the researcher has demonstrated adherence to the tenets of their chosen methodological approach, in this case GGT (Simmons, 2011).

3.7.1 Assessing quality within qualitative research

Qualitative research has been criticised as biased, it often relies on small sample sizes, is anecdotal and therefore lacks rigour (Hallberg, 2006, Bryant & Charmaz, 2007). Subsequently, it has been recognised that quantitative requirements for validity and reliability are not suitable for evaluating qualitative studies (Sandelowski, 1996). Others have argued that qualitative research conducted well can be unbiased, in-depth, valid and reliable, credible and rigorous (Mason, 2010, Anderson, 2010).

While qualitative researchers agree on the importance of producing research of a high quality, Denzin & Lincoln (2011) are critical of the need to shoehorn qualitative research into different propositions for assessing or evaluating it. They argue that qualitative research has plentiful methodological rules and interpretive guidelines, which they feel are subject to change and to different perspectives. They feel it is inappropriate to try to apply a single gold standard for evaluation of the plethora of qualitative research methodologies and approaches that exist.

Lincoln & Guba (1985) suggested evaluation of trustworthiness of qualitative research, which considers credibility, transferability, dependability and conformability. These elements of evaluation are perceived as equating to the assessment of internal validity, external validity, reliability and objectivity in quantitative research (Polit & Beck, 2012).

Regardless of the differing perspectives on evaluating qualitative research, as a novice researcher writing a thesis it was important to carefully consider how the current study could be evaluated.

3.7.2 Demonstrating rigour in the current study

Rigor in the current study was achieved by adhering to the GGT process, using reflexivity throughout, and maintaining an audit trail of all documentation for processes as they progressed.

Criteria for assessing the quality of grounded theory were posed by Glaser & Strauss (1967, p.237-250) and reaffirmed by Glaser (1978, p.4-6). They remain the standard by which the quality of a grounded theory should be assessed. In meeting the standard for quality in the current study the following processes were followed. In GGT the fit, relevance, workability and modifiability afforded to the substantive theory provide evidence of achieving trustworthiness. Trustworthiness and credibility in GT are addressed by remaining true to the method and avoiding re-modelling (Glaser, 2004). Trustworthiness of data was maintained by my ability to track my steps throughout the various stages of the GGT process.

Conceptual codes and categories emerged from the data as outlined in the figures provided at the start of each findings chapter, Chapters 4-7, and not from preconceived or existing codes and categories (outlined in the conceptual map figure

11 p.251). The substantive grounded theory identified (p.304) is able to interpret, explain and predict future critical care survivor behaviour given the same circumstances. A core concern was identified within the substantive area and is conceptually grounded in the data. This means the core category is significant and relevant because it is reflective of the participant experience and perceptions (see chapter 8, p.245). The grounded theory produced was amended when new and relevant data were compared to existing data and continually modified as new data emerged: producing new categories, properties or dimensions of the theory.

As an aid to rigorous grounded theory development Glaser (1998, p.40) proposed the following questions be asked:

- What is this data the study of?
- What category does this incident indicate?
- What is actually happening in the data?
- What is the main concern being faced by the participants?
- What accounts for the continuing resolving of this concern?

More recently Glaser (2001, p.123-124) has provided further clarification of reliability and validity in GT. The process of categories being constantly compared to vary them for application and to develop new properties, ensures that the theory is generalisable. These processes were fundamental to the emergence of theory in the current study. Glaser says the theory fits, works, is relevant and modifiable and credible. In terms of transferability Glaser says it transcends experience, it moves from description to a conceptual level and because it is abstract of time, place and

people it can easily be applied to different situations and still fit. This provides external validity in that the theory both fits the situation from which it emerged, but can also be generalised to other situations through constant comparison. These aspects from the current study have been outlined in the current chapter. This provides dependability where all categories and properties are constantly verified with new data or conditions requiring modification to account for variation and enhancing the theory. Finally confirmability and the problem of reproducibility, replication and objectivity is deemed by Glaser as not pertinent in GT because the goal is conceptualisation not description. The concepts once discovered, stand on their own and new data will only extend or modify the theory

Anderson (2010) points out that consequently a rigorous process is in place and emerging theory is therefore an original product of the research. Reflexivity (already discussed) is an important component of rigour.

Exploring research publications highlighted that individual interpretations of what constitutes GT abound and it was challenging to filter out variations of GT that could undermine my chosen methodological approach: GGT (Evans, 2013). An audit trail of the processes used to conduct this study has been maintained through the researcher's combined use of NVivo 10 and saved chronological documentation that could be produced on request. Glaser (2012) says that this is not necessary if his approach is used well. However, the researcher had to be realistic about her inexperience as a researcher, the responsibility of having been funded and the end point of thesis submission for scrutiny. Logically, it was important to methodically

capture the study development and progress. Therefore, providing traceable steps of the research journey was an important facet of this thesis.

3.8 Summary of chapter

This chapter has discussed research paradigms, ontology and epistemology, which inform the researcher's philosophical stance taken toward the research. The rationale for the choice of methodology was provided, a detailed exploration of grounded theory was presented ending with a focus on the selected GGT approach and application of it throughout the research design and data analysis process. Evaluation of the GGT study and contention surrounding rigour has been explored; identifying the criteria that are applied to establish the quality and originality of the grounded theory that is the end product of a well conducted GGT study.

The study aim of providing an in-depth insight into critical care survivor experiences, and use (or not) of a critical care diary during the first twelve months of their recovery, to inform development of theory and future diary use was achieved. This encompassed achievement of objectives 1-3. Objective 4 pertaining to environmental and demographic factors that may impact on perceptions of the diary was not found to be of relevance with the participants recruited in this study.

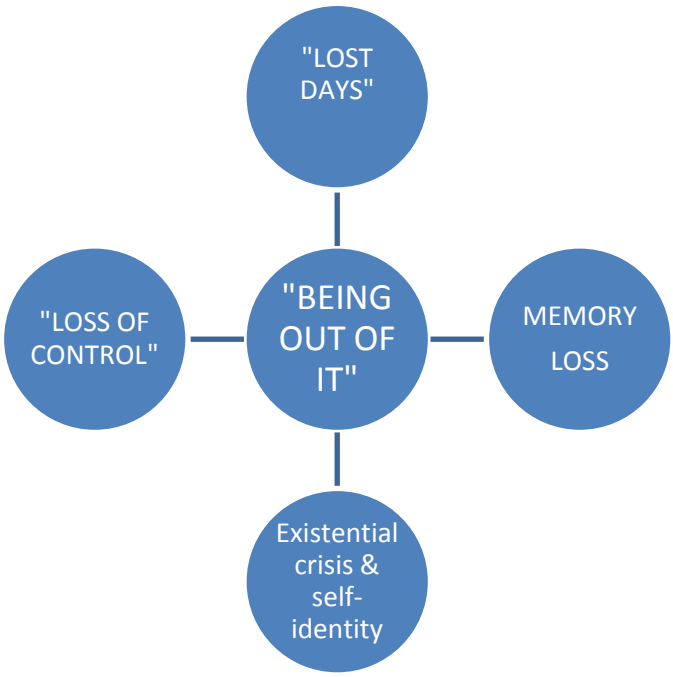
The next part of the thesis explores the conceptual categories in Chapters 4 through to 7. The conceptual categories that emerged are *"being out of it",* Recovery: *"is it*

normal to feel like this?", "*something I must know"* and finally critical care diary: *"it's a piece of jigsaw".* The grounded theory that emerged will be explained in Chapter 8.

The following figures provide a summary of the conceptual categories (central circle) and associated codes and the chapter in which they are discussed. These are replicated at the outset of each of the findings chapters 4 through to 7. They are provided here to sign post the reader to the ensuing content.

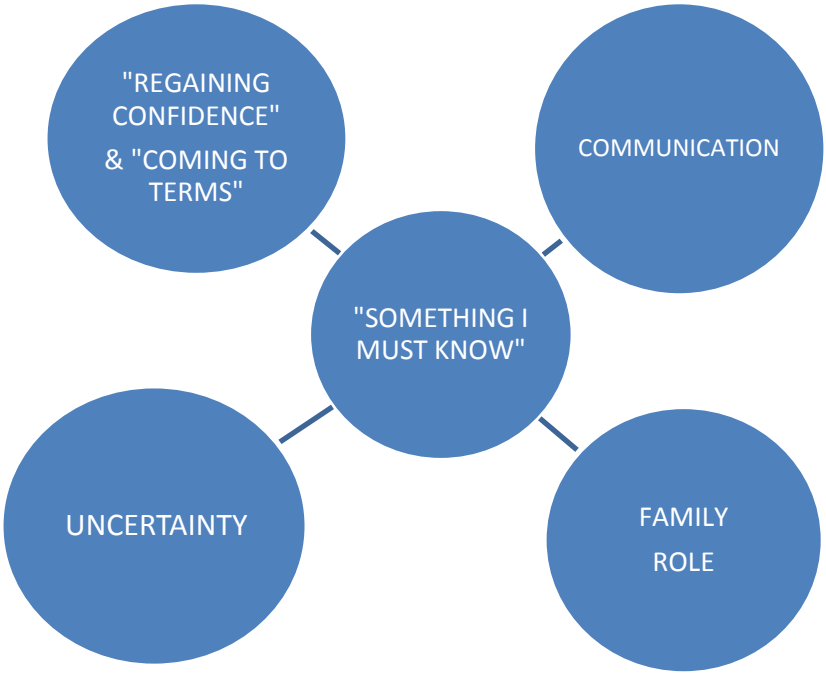
Figure 5: outline of chapters 4-7

Chapter 4



Chapter 5

Chapter 6



Chapter 7


THE DIARY PROCESS
BEING READY TO KNOW
CAPTURING WHAT HAPPENED
CCONSTRUCTING THE ILLNESS STORY
BENEFIT VERSUS HARM
DIARY ROLE
"IT'S A PIECE OF JIGSAW"

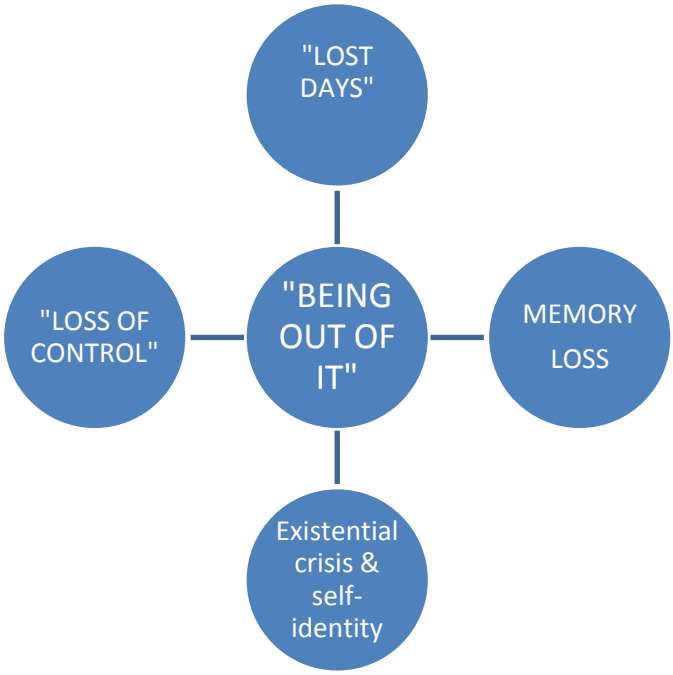
Chapter 4: “Being out of it”

4.0 Overview of chapter

This chapter aims to identify the longitudinal issues identified by participants in the study in relation to their critical illness experiences and potential critical care diary use, or not, over time. *“Being out of it”* (the conceptual category) represents participant’s notion of a period of unconsciousness. This also encapsulated *“lost days”* in relation to their time in critical care and this code explores the concerns they identified related to the impact this had on their existence; thus on their sense of identity. Participants shared concerns about *“memory loss”* and this code explores participants’ concerns related to not remembering critical care and on awakening, their awareness of surreal experiences that were difficult to differentiate from reality. Ultimately, participants described being left with a sense of “*loss of control”* and this code explores the impact this had on participants’ ability to relate to happened to them. Existential crisis and self-identity code captures the impact of the critical illness upon participants regarding the rift that now exists in their lives and how lost time and loss of control have impacted on their sense of self- identity and resulted in participants needing coherence to try to make sense of the life threatening event.

Figure 6 below provides an outline of the conceptual category and coding used as a framework for discussion in this chapter:

Figure 6: Conceptual category "being out of it" and associated concepts



Most participants used the exact words *"out of it"* to describe their critical illness experience. *"Being out of it"* has connotations about loss of self and control in sense of time, memory, and identity.

> *"…its part of my life that's gone which I don't know about, because I didn't know which day was what…" (Ian 2 months)*

As demonstrated by Ian in the quote above *"being out of it"* was a part of their lives that they could not account for and what happened, unbeknown to them, during that

time was a source of concern for those participants who wished to understand what happened. They were left reliant on others to authenticate their time in critical care. *"Being out of it"* was an unusual event for participants as in everyday life there is a sense of continuity and self-identity through active engagement and participation in things that happen.

4.1 "Lost days"

One of the underlying issues for participants pertains to the conceptualisation of their *"lost days"*, which required understanding of what happened during the rift in their life story for those who wanted to know.

> *"I think what I find the most difficult is I have lost ten days of my life haven't I? It's not like going on holidays...they are completely gone and there is nothing anybody can do about that is there?" (Emily 2 months)*

There is expression in the quote by Emily above that she needs coherence to make sense of what has happened to her, but at this stage of her recovery she has not found that.

> *"It's not real in some ways...I am accepting that it has happened, but it is quite strange to really have six weeks of your life and there is nothing... my friend said...about the riots in London and I went (shrugged shoulders) what? I didn't know because the family never spoke about that...Now and then things come up that I don't know." (Alice 6 months)*

Alice's quote highlights the fact that during participants' recovery they were continuing to try to piece together the story of their life during critical illness. Added to this there was the impact of trying to catch up with events that occurred in everyday life, be that family life or daily news. Alice talks about acceptance that this has happened to her at the six month stage of recovery. Participants expressed a need to understand what happened to them as a person and expressed the struggle they had with their self-identity when they were unable to consciously interact and engage with the world around them (Tembo *et al.*, 2012).

4.2 "Memory loss"

It is clear from Emily's quote that despite her feeling she has no memory of critical care; in reality she does have some limited recall:

> *"...when I was out of it I want to remember things, because I think that would explain it. Maybe I could come to terms with that better, because at this moment in time there is nothing...just a bit of a spaceship...and can remember being rolled over to be changed." (Emily 2 months)*

The uncertainty related to her memory does seem to be a cause of unease for Emily, who describes herself as a private person. She clearly feels anxious about the vulnerability of others being responsible for her dignity and privacy.

Ringdal *et al.* (2006) and Samuelson *et al.* (2006) identified that over 50% of intensive care patients retain factual memories regarding their admission. Interestingly Toien *et al*. (2010) point out that factual memory in association with critical illness may actually be related to increased risk of developing PTSD.

The data in the current study suggests that although participants described dreams and hallucinations it was not possible to ignore that some may have been triggered by actual experiences: Beth trying to get attention and being ignored, then being incontinent:

> *"I had vivid dreams... He kept disappearing and walking about with a piece of paper in his hand and writing. And I was there for ages, so of course I wet myself, but this is a dream, because that wouldn't happen on a ward. Well I wouldn't have thought." (Beth 2 months)*

Alice highlighted that even at six months she felt confused by the blurring of reality and dream state that had occurred in critical care:

> *"Now and then I think, did I remember, did I hear that or did I make it up or did I think I heard it or not." (Alice 6 months)*

Clara described how strange the high dependency unit environment felt to her and the manifestation of stories that she lived through using poignant metaphors and the association between surreal and reality:

"...It was just so alien, it was almost like surreal...Nothing was making sense. Why were these numbers up if they weren't the dates? Why did I keep going into this sort of, you know as if you were on some sort of trip, going into something or other? You know and they were desperate at night to get me to go to sleep and I couldn't sleep. I was wide awake, starring, involved in this whole episode of stories." (Clara 2 months)

At six months the stories remained vivid for Clara and she still felt as if it was real, but she tried to explain why this occurred and that perhaps it was down to the manner in which her mind was trying to make sense of what was happening to her:

"...the storylines are still very very vivid to me, as if it was a reality, you know and its almost as if everything that has gone into your subconscious is coming back and in very strange formats, like people in your life were in these storylines and everyone who has touched you in some way was appearing in them and it was as if the mind was emptying itself of everything, but putting it into weird and wonderful storylines and it was incredible because it was so real..." (Clara 6 months)

Clara shows insight into how she felt her psychological well-being was maintained by her experiences of trying to understand the surreal and the reality of her memories and dreams. The diary helped Clara gain insight and in conjunction with discussion with her husband helped her to understand what had happened to her in a chronological and coherent manner.

It is evident from the literature that ‘conflict resolution’ in terms of marrying memory and experience with reality is not something that all patients wish to adopt (Adamson *et al.,* 2004). Indeed some would argue that expecting certain patients to confront what has happened to them could actually be detrimental and incur psychological harm where there was none (Tahir, 2014).

Participants demonstrated more detail about events in their interviews at six and twelve months, but this seemed to be due to their incorporation of the stories their family shared with them about their time in critical care and in association with critical care diary use. In some cases when they visited the critical care unit to collect their diary it prompted some new memories about the environment, such as light versus darkness of the unit, the curtains or bed area.

“Memory loss” or perceived amnesia was expressed by all participants, even if they could provide some overview of distorted memories; their perception was that they did not remember anything. Over time they were better able to integrate what they now understood about their critical illness experience to form a sense of coherence of their missing life story related to that missing time.

4.3 Existential crisis and self-identity

Participants in the current study referred to their period of unconsciousness and subsequent lack of memory as a period where they were not 'living':

> *"I don't feel I exist and that's not easy to accept, these days have gone, because to you it is the same day …I find it really weird... It's like you have gone off the face of the earth and it's hard to explain really. Whereas people just go on with their life and you take it for granted don't you." (Emily 2 months).*

Some participants found it an uncomfortable concept to try to grasp; that they were unconscious, but life for everyone else continued. Participants expressed a need to understand what happened to them as a person and their identity when they were unable to consciously interact and engage with the world around them:

> *"I think I get frightened of the thought of being sort of lost, if that makes sense, of the fact of waking up there and then sort of like dying in there. That freaks me out a little bit, thinking would I have been lost somewhere..." (Emily 6 months)*

The sense of loss of self- identity and impact on Emily continued over the course of the year of her recovery:

"It would be nice for people to feel secure really. You feel as if you have been lost then…cos the only connection I had with the hospital after was seeing the Consultant and I think that was a good thing…cos everybody wants to be reassured don't they?" (Emily 12 months)

Emily's quotes depict how she struggled with her recovery because she did not feel reassured and supported following her critical illness, despite having her diary.

Clara provided a concise and insightful explanation of how she felt having obviously given it a lot of thought over the year:

"...because your memories are there, they are made when you are awake and you can file that away, but you know, it's that black hole of when you weren't with life..." (Clara 12 months)

This life threatening event has happened to them, but the critical care phase is something that participants do not feel they experienced and therefore they feel a sense of detachment from it. The 'unknown' dimension that this adds to their already complex experience is challenging for participants to comprehend.

There is an underlying impact of critical illness on participant's identity and comprehensiveness of their life. This is evident in the way participants refer to themselves as not living or existing and in the context of perceived amnesia, lost time and their existence.

Participants appear to be questioning their existence during the period of time that they feel they cannot remember. The fact that these critical care survivors have suffered a life threatening event (with no memory of it) seems to have triggered what is termed an existential crisis. This is said to occur when the answers to questions pertaining to the meaning of life and our place within it fail to provide comfort and peace of mind (Henoch & Danielson, 2009).

The majority of publications available focus on palliative care (Ross, 2006). However the concept is not exclusive to end of life situations and descriptions of existential/ spiritual concerns are raised by participants in the current study in relation to the life threatening nature of critical illness. McSherry & Ross (2010) highlighted the importance of spiritual components of the person (mind, body and spirit); its role in recovery following illness: attaining and maintaining health and well-being and impact on perceived quality of life. Whitehead (2003) postulated that existential health requires tangible resources, finding meaning in life events and evaluating elements of 'self'. Fundamentally he says that recognition of existential health 'suggests that individuals' possess a capacity to initiate a self-healing process by drawing upon an inner strength resource' (p.679). Whitehead (2003) seems to be describing human resilience and a personal positivity or determination to overcome illness and he criticises HCPs lack of knowledge and understanding of the importance of using this to improve patient outcome following illness. He suggests that if HCPs assessed existential health it could enhance patient's total health and well-being.

Existential concerns have been attributed to two main themes in cancer care around the struggle to maintain self-identity and the threats to self-identity (Henoch & Danielson, 2009, p.227). In the case of participants in the current study their self-identity has been disrupted by the period of unconsciousness or 'being out of it'. The subsequent threat to their self-identity manifests through their descriptions of perceived amnesia of their critical care admission and the rift this memory gap has left in the timeline of their life story. All the participants expressed a need to know what happened to them.

4.4"Loss of control"

A consequence of the memory loss and *"being out it"* was the *"loss of control"* that participants experienced. One aspect of *"loss of control"* pertained to the care they received from HCPs as outlined below:

> *"It's not the first time I have done this for you, you know, washing me head to tail and well of course I didn't know who the hell he was, did I? I thought he was a vicar or a preacher or something. It was strange why I would think that. I probably wasn't compos mentis upstairs that morning. It was my first time really awake." (Beth 12 months)*

It must have been unsettling hearing that while you were *"out of it"* someone was providing intimate care for you. The trusting relationship that would usually form

between the nurse and patient had not occurred because the participant was unconscious and unable to interact.

Emily focused on her *"loss of control"* in the context of reassurance about maintenance of her dignity and privacy. She was particularly perturbed that her husband may have allowed visitors to see her and made it clear that she would not have liked that:

> *"…the thought of somebody coming and walking around, oh I would have died. Not that I would want to stop that for people to get over it, but I think out of respect for people that are really really poorly. These people they are out of it and I know they don't know who has come in or what, but oh I don't think I would have liked it." (Emily 2 months)*

There was also the *"loss of control*" over their independence due to physical debility that resulted from their critical illness event:

> "*...I had gone from being the person that was always taking the dog for a walk or out in the garden or doing something or other to someone who was laid there incapable of movement." (Clara 2 months)*

Clara, Fran, and Emily used the metaphors "*blob", "lump"* and *"beached whale"* respectively to explain how they felt .They imply that they felt dehumanised or depersonalised by their experience and lack of control over it.

Waking to eventually be well enough to start to comprehend what has happened is bound to be a challenge, but arguably one that HCPs should be able to acknowledge and address. However, the current study data suggest that this is not the case and HCPs assumptions of lucidity may not match the cognitive ability of the patient. This indicates that explanations may need repeating, and to be included in the diary, throughout the patient's transfer to the ward and prior to and after discharge home to optimise the chance that this information has been understood and retained.

The associated *"loss of control"* in terms of *"lost days"* and concept of time, plus their reduced physical ability were significant issues that participants strove to overcome. Shock, denial, avoidance and incomprehension were evident from their descriptions in relation to their critical illness. The participant data discussed in this chapter demonstrate that unconsciousness leads to a rift in participants' normally coherent view of their lives in relation to place, time and context and they are left struggling to resolve it.

The participants in the current study expressed disbelief that this happened to them. They woke with a rift in their life story which was hard to comprehend and left them with vulnerability and unease. The perceived amnesia in participants ranged from a week for Alice, Diane and Ian, ten days for both Beth and Emily, six weeks for Graham and Clara. The amnesia meant that participants felt they had no concept of the passage of time and in effect they had experienced a period of suspended animation being taken ill one day and waking to find it isn't the same day. The notion

of not being an active participant in events that are hugely significant is a complex one to comprehend for the participants.

"Loss of control" in relation to illness is not new and has been written about by many over the years (Bandura, 1977; Antonovsky, 1979; Charmaz, 1999). According to McCormick (2002) ambiguity and vagueness about illness combined with a lack of information means patients experience loss of control and uncertainty

4.5 Changes over time

At the interview at two months participants could not comprehend what had gone on and were still striving to piece events together to make some sense of it and there was hesitancy to face the reality of what had happened and some participants questioned if they even wanted to know; if they could cope with the information even. At this stage not all participants had collected their diary and some were uncertain if they would. There was reliance by participants on their significant other to help them explain their story of what had happened to them. It seemed important that they had it right when explaining it to the researcher. In reality this process may also have benefited participants in potentially being the first opportunity for them to articulate the critical illness events as a timeline. There was a clear disconnection between the participant, concept of critical care and staff who may have been involved. Participants described struggling with how this could have happened to them.

At six months participants had drawn together information from family, reading their diary and talking to HCPs at appointments if they had any. At the interview at six months all participants had read their diary, though some omitted emotional aspects, such as where family had made entries as at this stage they still found that to emotive to deal with. Some participants spoke about the shock they felt when they realised how ill they had been. Participants were less reliant on family to express their story than they had been at the initial interview. The explanations were more detailed and in their own words and they explained how they had explored things that did not make sense to them, such as looking something up on the internet or asking a HCP, or GP.

At the twelve month interview participants seemed comfortable recanting their critical illness story and it was articulated as their own story with a reduction in, or no need to refer to what family or others said to them. They were more confident in providing quite detailed explanations about their illness and certainly more in control over the timeline of the events and how they were recovering.

4.6 Summary of chapter

"Being out of it" identified participants' perception of the rift in the normally continuous uninterrupted timeline of their lives. Their sense of self-identity and control was embedded in being able to account for this missing period. Therefore needing coherence emerged as central to participants' concept of themselves as a person. Although they could not remember the critical illness events, they wanted to

know what happened and this is where the diary could play a part in their recovery process.

The issues of a rift or disruption to the normal life timeline and impact on self-identity, and coherence is explored in chapter 8 as part of the emerging theory.

Chapter 5: Recovery: “Is it normal to feel like this?”

5.0 Overview of chapter

The aim of this chapter is to explore the conceptual category, recovery: *“is it normal to feel like this?”* which incorporates codes *“mentally what a patient has to go through”,* recovery and progress: *“the struggle”* and “*realise how ill I was”* and sub code *“anniversary”* of their critical illness. The category and associated codes highlight the difficulties participants shared in trying to understand their critical illness and the impact of this on their recovery. The longitudinal approach used in this study provided opportunity to identify impact of the critical illness on participants over a year in their life post-ICU discharge. It also facilitated insight into what worked and did not work in terms of aiding their recovery process and how a critical care diary had a part to play or not.

The conceptual category and associated concepts, outlined below in Figure 7, form chapter subheadings that facilitate critical exploration of participant experiences and outline the challenges they perceived in relation to their recovery.

Figure 7: Recovery: “Is it normal to feel like this?” and associated concepts.

5.1 “Is it normal to feel like this?”

Participants shared that following their critical illness event that they did not know how they should feel or what to expect.

> *Researcher: “Do you try to explain how you feel and why?”*
>
> *Emily: “Yes and all I can say is it isn’t normal. I can’t explain what that is. Perhaps it is because I don’t want to go there, because I don’t want to find out. “(Emily 2 months)*

In terms of her diary use Emily said:

"*Haven't really gone into it, just flicked through it, but obviously some of it is not quite finished yet. I think he (husband) was going to get it ready and do it, because I haven't really read my get well cards either." (Emily 6 months)*

Emily found it difficult to want to explore what happened and therefore like her illness she avoided having to deal with it. This resulted in her feeling vulnerable when she saw her GP because she describes herself as an anxious person and this is evident in her description:

"This week now I have had to go down the doctors yesterday and I feel as if I am putting it on…I felt as if the doctors was looking at me as if to say oh you are so simple…Other people it wouldn't bother them would it?...If I am not careful I will probably make myself ill" (Emily 12 months)

More evidence of her avoidance and anxiety is provided when she shares that family do not talk with her about it and she does not really want that from them anyway:

I think everybody just knows that its coming up to (the anniversary) to the point where nobody is talking about it…I think we are hoping it will just come and go, whether that's a good thing I don't know, not talking…but everybody deals (with things) differently don't they?" (Emily 12 months)

Emily was a different character to the other participants, but her interviews shed some light on why patients may not want their diary. Her psychological issues potentially existed prior to her critical illness and were then exacerbated by the

situation. These initial sections of the chapter do favour Emily because she provides an antithesis of other participants.

5.2 “Mentally what a patient has to go through”

Emily emphasised the point that ward based nurses do not necessarily have the knowledge and understanding about what psychological impact critical illness and admission to critical care may have on a patient.

> *“...but I think it would have helped to have had something, don’t get me wrong, the nurses are so busy...it’s just routine, isn’t it?..I don’t think they realise mentally what a patient has to go through.” (Emily 2 months)*

This is something that could potentially be addressed through education and training and exposure to patient stories about their experiences. Emily never felt anyone took the time to ask her how she was feeling or to try to explain what happened to her. Apart from her husband’s story of events she had no acknowledgement that she had been through something life threatening and traumatic.

> “*I think the first time was over so quick and I was home. You put on this brave face that everything is fine and that…I wouldn’t show them how I felt. I suppose you didn’t have the pressures of home life did you?” (Emily 2 months)*

In the quote Emily clearly uses avoidance and tries to cover up how she is actually feeling as that is a coping mechanism, but following her critical illness coping has obviously been difficult and she has had no means of sharing that apart from through the interviews. She was closely monitored by her GP as she had been there when she deteriorated and had to call the ambulance. So it seemed she felt able to discuss things without fear of not being believed.

> "*Just go straight up to the doctor if there is anything…I had to phone in for a sick note for work and I think if I had said I wanted a year off he would have given me a year off…I went from the doctors, they actually phoned the ambulance, they actually know how ill you are, don't they? He said if you have any problems just ring and I will come up straight away." (Emily 6 months)*

It seems that for people like Emily, who use a façade of coping, a relationship based on trust is needed to help them recover; a diary alone does not suffice. There is a need to feel that the person will believe them before they feel able to open up and be honest about their true feelings. Different coping strategies require different means of support and sometimes a diary is not the best option and perhaps follow-up, support groups or counselling over time are alternatives that need to be considered.

The difficulties participants had because they had little or no memory were challenging to their recovery:

"Sometimes I wish I could remember…well people telling you and going to the places where you were so ill, it is an eye opener for you and you realise the care that you had." (Diane, 6 months)

Having a diary for some aided in providing some awareness of what happened and reassurance about care received as demonstrated in Diane's quote above. However, whilst knowing how ill she had been was an eye opener, Diane also described other feelings during her recovery at six months:

"*getting quite short tempered...Things have got to run smooth for me otherwise I get all het up. Whether that is a normal thing I don't know" (Diane 6 months).*

In some cases there were lingering potentially chronic after effects that affected their mood and thus their recovery.

" Still I have got a really bad back I have had that since I came out of intensive care, but I have got an appointment with my doctor this month…get down in the dumps sometimes." (Diane 12 months)

Depression and PTSD have been highlighted as consequences of critical illness Hopkins *et al*., 2008, Jones *et al.,* 2010). Added to the physical debility is the emotional and cognitive burden that often persists after critical illness (Rattray *et al.,* 2010, Jackson *et al.,* 2012).

When participants feel anxiety about what occurred and they are unable to make sense of events this can start them on a positive or negative cycle of rumination in their seeking answers:

> *"If my friends and that eventually read the diary I want them to see…how ill I was, and what they did… but so and so went, she was in and I'm like, then my husband's like, well you were far worse than them, but was I? So how was I worse than them then? It would have been nice to have said, I can't believe how ill you were." (Emily 2 months)*

Some participants highlighted that without their diary they would have had a lot of unanswered questions that they would potentially have been ruminating on.

> *"…I think I would have been doing a lot of wondering and it would have been buzzing around subconsciously in your head all the time I think, knowing me." (Beth 6 months)*

Prolonged rumination can negatively impact on health and well-being (Smith & Alloy, 2008).

According to Hefferon *et al.* (2009) people who experience traumatic events can develop anxiety related to stressors that are beyond their control. In some cases this psychological impact can be long lasting, even inhibiting return to normal functioning. Some researchers believe that this is not true for all individuals and that after

traumatic situations some people will not only recover after the episode, but that the struggle with adversity can actually increase their functioning afterwards (Charmaz, 1999; Bonanno *et al*., 2011). This appears to be true of Clara:

> *"...it is a journey and it's a journey that's continuing for me and you can't sort of think right that's over now do this, this and this, because it isn't, when you have been through the trauma, major trauma, whatever you want to call it, there isn't an end date with it, there is an acceptance of what you have been through and there's a sort of right, ok I ask less questions, I don't need the reassurance all the time...but you are never totally free of where you have been...life's a journey anyway, but this has just been part of it. You know and the cliché, "what doesn't kill you makes you stronger" is very true." (Clara 12 months)*

In Clara's case she felt her critical illness journey, along with her diary and putting the pieces of what happened together to find coherence actually made her a stronger person and she did not let it have a negative impact on her self-identity, rather it became a positive.

Overall the psychological wellbeing of participants over the period of the longitudinal study demonstrated that certain triggers had a negative or positive impact. The ability of the participant to gain clarification from both family and the diary is evidently important and is noticeably lacking for Emily.

5.3 Recovery and progress: the “struggle”

It is important to note that recovery after critical illness is challenging, especially when participants were not always sure why they felt the way they did. As Emily explained, participants did not know how they should feel after their critical illness:

> *“Is it normal to feel like this?..nobody said to me look you might be feeling a little bit weird...and that is normal.” (Emily 2 months)*

How someone should feel after critical illness may differ between individuals as their illness trajectories will not be identical and people have different personalities and ways in which they cope against adversity.

> *“I took away the toilet seats about a week ago and I said to him we won’t ask for them to be taken yet, but let’s see if I can cope without it. Don’t even think about it now” (Clara 2 months).*

Clara had a goal driven approach to her recovery as demonstrated above, with her taking slow steps toward regaining her independence and moving on with her recovery.

Like the other participants, Alice found it difficult to understand how her critical illness now meant she had reduced physical ability:

"...It was a shock to me how weak I was...I thought I was going to come out of there and be on my feet...That was the hardest part I think, realising what I couldn't do and I couldn't understand why I couldn't do it, of course it was only because I was laid down for so long that I had lost the use of my arms and my legs. Physically and mentally then I was fine, but my body had to catch up with it all." (Alice 6 months)

Alice quote demonstrates that there is a mismatch between participants' expectation of their body following their critical illness and the reality of what they are able to do. Although she implies that she felt physical and mentally well, but that her body did not represent that for her. So it is a dichotomy in that perhaps she still does not fully accept or understand what happened to her. If you cannot remember something then it is clearly difficult to make sense of things and come to terms with it afterwards.

Then there is also the reality of coming home and the realisation that things are more of a struggle when you try to return to normal family life. It is also feasible that Emily was unrealistic about how she would be physically and psychologically once home and away from the security and support of being in hospital. She acknowledges this in the quote below:

"I think when you are in hospital you are in this like a bubble where you feel really really well because I did feel really well when I was the last sort of like two days in hospital." (Emily 12 months)

Furthermore Emily felt her diary was too brief and when she compared it to what her husband told her the stories differed. The difference for Emily being that her husband could tell her a lot, but reading the diary it was very brief, only capturing her initial admission superficially. She was unable to gain any confirmation; therefore validation or affirmation of how ill she had been or make sense of the story from HCPs perspective.

She was so anxious on the day she collected her diary that she did not ask any questions. There was no follow-up opportunity and in her interviews she was still trying to make sense of it all. In Emily's case she said she would not have wanted her diary if it was just up to her. In some ways collecting the diary has failed to allay Emily's anxieties, and instead has possibly increased them. The way Emily would usually choose to cope would be denial and avoidance and she demonstrated this in her inability to confront years of warning signs that she was becoming unwell.

Being critically ill and hospitalised for a prolonged period of time is bound to be a significant experience for patients, but the long term impact was not a welcome one:

> *"Well I have been tired a lot since coming out of hospital and I don't seem to be picking up as I think I should be…but I would like to go back to how I was feeling before I was ill. It's coming up to a year now." (Beth 12 months)*

Some participants saw their recovery as a personal challenge to overcome like Ian. He was determined to get better and he saw things in a positive light, which seemed to help him move onwards with his life:

> *"It was not a terrible time for me really. My mobility was the worse thing…I just knew I was going to get better." (Ian 12 months)*

The critical care diary was a means for some participants to create a connection with their illness story and to try to make sense and understand what they had been through so that they could try to come to terms with it.

> *"I think that was the biggest one was just coming to terms with it all. I am convinced that a lot of the time I was in hospital I was still in shock… You know coming round from it all and everything with it and I found my diary and I did read another piece. I have read it and cannot say how much that diary is meaning." (Clara 12 months)*

Clara explained during her interview that she had not appreciated what had happened and the recovery process, for her, was about coming to terms with events. She felt that reading her diary and discussing that with her husband was pivotal to her acceptance of her critical illness and the debility that she was left with afterwards.

Reflecting on her critical illness journey over the year Clara explained:

"… it's all part of the picture and if you are feeling a bit sort of oh sorry for yourself or whatever, you can go back to that and think hang on a minute I have been through hell and back. It has got to come out in your body the same as it has got to come out mentally… they all think is the trauma coming out in me… You know we continue to go through the journey and we are where we are with it, you know, and I am very grateful to it…I think people are shocked with my journey and I don't think people always believe me with my journey. You know I have got the physical evidence of the journey."(Clara 12 months)

Clara suggested that she had begun to forgive her body for letting her down and to accept that the things that occurred were a response to a life threatening event. She said she had come to terms with the fact that her body had shown outward evidence of the traumatic experience in the same way that she acknowledges it has to manifest psychologically too. Her quote above demonstrates how participants relate to their recovery as a *'journey'*, but that they are not always sure people appreciate what it entails. The diary can form a means of sharing the story with friends and family that were not there at the time.

Not knowing what happened and why they were so physically debilitated were difficult for participants to comprehend. Their recovery was partly dependent on information seeking to gain knowledge and understanding of what had actually happened to them so that they could put things into context and appreciate why their body was reacting in this way. Having experienced these complications, there was

an appreciation that their rehabilitation had taken and is still taking time. At twelve months study data indicated that recovery was continuing for some.

There was an obvious disparity in service provision and support between participants. Clara had been transferred to a specialised rehabilitation hospital and after discharge home she was provided with support in washing and dressing by the START team. This service was not widely available to the others.

> *"I have had a lot of help from, have you heard of the START scheme?...What they do is they provide 6 weeks of care as you come out of hospital. My only real need was to have supervision with the shower, but they provided me with the toilet adjusters...I am still using the bath seat and they are going to put grab rails for me in the shower... every morning they come in now and help me shower." (Clara 2 months)*

Clara found the support she had very enabling in the beginning of her rehabilitation. This was the opposite of Graham's experience, where he was transferred to a main hospital ward that did not specialise in rehabilitation and then sent home with no on-going support:

> *"Yes but it was 5 weeks after I come out of hospital and chasing them up a few times that eventually I got some physio." (Graham 2 months)*

The same was true of Ian's experience where he had been the longest inpatient of all the participants and was sent home unsupported apart from family and friends. They had to help him into his house as there were steps:

> *"That is one thing I am surprised at that I haven't had any form of physiotherapy this end; out of hospital physiotherapy. It's not knocking anybody down there on the physio side, because they could only do what you would let them do anyway, but I am ready for more now and I think my progress would be quicker if I got some." (Ian 2 months)*

Diane makes an interesting observation that there is no means of following up the patient afterwards. She obviously valued being part of the study because she did have opportunity to talk about her progress.

> *"At the time when I first came home if I needed anything I had close family around me. I haven't had anybody else come and see me since I came home mind. All I have had is you. Nobody else has been to see how I am progressing or anything…somebody to talk to you, somebody just to see the progress that you are making." (Diane 6 months)*

The use of specifically tailored rehabilitation wards was seen as pivotal first steps to recovery by the two participants fortunate enough to have been provided that option:

> *"I know they are closing these little hospitals and it's such a shame cos they are so wonderful. The support you get there and the encouragement is*

absolutely lovely. No, I think I have been pretty lucky actually with the support that I have got" (Alice 12 months)

The transitional period between critical care and the ward environment needs careful consideration and service provision should consider the difference in patient needs after critical illness, by assessing the appropriate next step in the patient journey and whether it should be rehabilitation prior to home:

"I was encouraged to do things for myself obviously, because that's the name of the game, they want you fit, but there was always a sense of encouragement and that with it and that you weren't a nuisance; that everyone was helping you on this journey you were going through." (Clara 12 months)

The benefit of a specialist rehabilitation ward for Clara and Alice was that it gave them time to regain confidence, through encouragement after what they had been through.

Critical care survivors face a protracted recovery that can take months or years before a return to the health that they had prior to their life threatening illness (Rattray, 2013). Furthermore, some may never fully regain the health they might wish to achieve (Ramsey *et al.,* 2012). Recovery and rehabilitation seems to be about facing the 'limitations' associated with admission to critical care; overcoming those that are feasible; accepting that 'time' may be required to heal or eventually, that realistically optimum recovery has been met.

What these experiences demonstrate is a lack of awareness by the HCPs and supportive services about what individual patient's needs are following critical illness and appropriate supportive measures are not consistently assessed and provided according to a needs based process. Clearly continuity of care between hospital, discharge and home could be improved.

5.4 "Realise how ill I was"

This code considers the enormity of the critical illness, which is a blank for participants. They have to rely on being told what was wrong, what was done, what the challenges were, how they overcame them. Some of what occurred can be technical and diary use may or may not capture the depth of detail and honesty a patient may require.

> *"...I think because you are out of it. I don't think you can appreciate how ill you've been." (Emily 2 months)*

Use of a diary is dependent upon what it contains and whether it shares the peaks and the troughs of events clearly enough to correspond with what family have said. Being so honest in a diary may expose people to reading something they are not yet ready to know and could be detrimental.

"God I must have been ill. Yes I don't think it has sunk in to me really. I suppose I don't really know how ill I was. Perhaps I haven't accepted that I was that ill, because I was out of it." (Graham 2 months)

Graham makes the point that it is hard to accept how ill you have been and what has happened, when you have been unconscious throughout it.

It is clear from the words participants used that they saw their life threatening illness as a battle that staff 'fought' on their behalf:

"If I hadn't have gone into critical care I wouldn't have been here today, because they fought for my life. You know nobody thought I was going to come out of there." (Diane 6 months)

Recognising how ill they had been was a step forward in participants' ability to focus their recovery in a realistic manner. Acknowledging that they could have died and being grateful to the HCPs involved in ensuring they had a future was important. Deacon (2012) highlighted that for critical care survivors it is just the beginning of their journey from surviving the life threatening event through to regaining their lives in the aftermath.

Additionally hearing the term life support through reading his diary made Ian all the more aware of his mortality. Although he knew he may not survive the use of this term was significant to his understanding of what happened to him:

"I knew I had been in intensive care, but I didn't know I had been on a life support machine and I only knew this, since I seen you..." (Ian 6 months)

Harry did not want to know what went on during his admission to critical care, but shared that he had been critically ill after a car accident years before and he did not want to relive that. So in some sense the current critical illness was a trigger for Harry remembering an old traumatic event and his way of coping was to ensure that he did not have his diary to read.

"I think about how the hell I am still here when I was so ill, but I am here and that's the main isn't it?" (Harry 6 months)

Harry's situation demonstrates that having a diary may not be beneficial and may even perhaps be harmful for some people in some circumstances.

Some participants expressed relief at surviving a life threatening event and some saw it as an opportunity to make the most of their life:

"I'm still lucky to be here so that's it, get on with life" (Alice 12 months).

Like other participants, Alice had put life on hold until towards the twelve month period of her recovery when she had started to accept that her condition was now going to be a chronic illness.

5.4.1 Anniversary

While participants had previously been positive about their recovery as the year post event approached there were two distinct paths people took. One was very much about continuing to move on with their lives, to feel able to go on holiday without fear; the other was now coming to terms with the fact that their illness has been a challenge to cope with, is perhaps now a chronic debility, some had psychological symptoms as a result, even when they did not expect that to happen.

> *"I just felt like I was trapped...I was thinking horrible things which is weird, why a year after? I wasn't even thinking oh it's a year or anything. Well this time last year look I was in hospital. I expect it was stress of Christmas coming up, but it has taken me until now to sort of get rid of it then, which is weird." (Fran 12 months)*

It seems that for Fran the anniversary affected her subconsciously and it was similar for Emily, but she experienced the smell of the hospital, making her recollection all the more vivid to her:

> *"I don't know whether it's coming up to a year, but the other morning I got up and I could smell the hospital and it's just little bits of flashbacks you are having, you know, that I perhaps haven't had really, but whether it's coming up to a year and because it's playing on my mind." (Emily 12 months)*

It seems the anniversary date did act as a negative psychological trigger for some participants. The anniversary of the critical illness was also a marker for the length of

time for physical recovery for participants and also a realisation that full recovery might never occur and that they might have to adapt to the lingering limitations that formed the legacy of their critical illness.

People who experience traumatic events can develop anxiety related to stressors that are beyond their control. In some cases this psychological impact can be long lasting, even inhibiting return to normal functioning (Cuthbertson *et al.,* 2010, Elliot & Rattray, 2012, Rattray*,* 2013). Some psychology researchers believe that this is not true for all individuals and that after traumatic situations some people will not only recover after the episode, but that the struggle with adversity can actually increase their functioning afterwards (Hefferon *et al.*, 2009). This appears to be true of Clara:

> *"...it is a journey and it's a journey that's continuing for me and you can't sort of think right that's over now…because it isn't, when you have been through the trauma, major trauma, whatever you want to call it, there isn't an end date with it, there is an acceptance of what you have been through...but you are never totally free of where you have been...life's a journey anyway, but this has just been part of it. You know and the cliché, "what doesn't kill you makes you stronger" is very true." (Clara 12 months)*

Participants refer to the words '*accept'* and *'acceptance'* and it is clear that their critical care admission and resultant sense of *"being out of it", "lost days*" and *"memory loss"* manifest as incomprehension of what has actually happened to them. Recovery includes their experiences of both psychological and physical ramifications following critical illness. Their understanding of how ill they have been seems to be an on-going process throughout the year of their recovery captured in the current

study. Importantly, over time it appears that as they build their critical illness story from the variety of sources available to them, that they are able to reach a stage of coming to terms with events and eventually acceptance of what has happened to them. This quest to piece together the chronological story of their *"lost days"* and of discovering and accepting how ill they were is an enormous challenge to their recovery process.

5.5 ICU survivorship

ICU survivorship is an emerging topic in relation to critical care and this is linked to an aging population, an increased demand for critical care use and improved mortality following critical care intervention (Iwashyma, 2010, Needham *et al.,* 2011). The resulting effect of this is the increasing numbers of critical care survivors and the growing evidence that has identified sequelae of short and long term physical, cognitive and mental health problems that form an on-going health related legacy for critical care survivors (Sukantarat et al., 2007, Desai *et al.,* 2011). The impact on critical care survivor's quality of life can be significant with on-going cognitive and physical debility (Ehlenbach *et al*., 2010, Iwashyna *et al.,* 2010). Current evidence from research suggests that there is a realisation that critical care should lead to further transitions of care provision to optimise recovery in the critically ill.

Despite recognition that critical care survivors need support, two participants had to chase for physiotherapy after discharge home (Graham and Ian). There seems to be a lack of co-ordinated aftercare for critical care survivors. Participants had different

experiences of rehabilitation during their recovery and as mentioned previously Alice and Clara were sent to rehabilitation wards that were able to cater for their needs after their critical illness.

Rattray (2013) aimed to provide an overview of physical and psychological problems faced by critical care survivors that can have a detrimental impact on their HRQoL. She argued that recovery following critical illness is an increasing problem internationally. According to Salisbury *et al.*, (2010a) current critical care rehabilitation is *ad hoc* and inconsistent and poorly coordinated, if available at all. Emphasis on service provision in critical care is beginning to change with rehabilitation of critically ill patients starting whilst in critical care and this requires a change in HCPs mind set to focus on early mobilisation and exercise (Truong *et al.,* 2009). Furthermore the team involved needs to have the appropriate training and skills for early mobilisation, planning and coordination of the challenging manoeuvre required with critically ill patients and the critical care associated paraphernalia (Schweickert *et al*., 2009, Bassett *et al.,* 2012).

Cancer care faced a similar survivorship challenge that is now at the forefront of critical care provision. As a result cancer care is further ahead in the strategies that have been instigated as a result of cancer survival increasing, which has in some respects altered cancer from a life limiting disease to a living with a chronic condition or in some cases recovery (National Cancer Survivorship Initiative (NCSI) 2015). This recovery pack could also be adapted to meet the needs of critical care survivors (See figure 8 below)

Figure 8: National Cancer Survivorship Initiative (NCSI)

Differences in participant behaviour and needs were evident over time. Some seemed to find a way to accept what had happened and these participants were most likely to have a positive attitude toward their recovery and a determination to progress (Alice, Beth, Clara, Diane Graham, Ian). Some participants struggled and made negative connections to their experience and appeared to use denial or avoidance strategies in relation to their illness (Emily, Harry, Fran). However as the anniversary of the critical illness approached participants shared anxiety about their experiences. Mental health, psychological well-being differed between participants; some shared experiences of anxiety, depression or panic during their recovery (Alice, Beth, Emily, Fran, Harry); while others seemed to adapt and cope (Clara, Diane, Graham, Ian). Similarly the physical debility participants faced led to different

experiences: none said they had returned to the level of health they held prior to their critical illness. This finding emphasised the significance of aftercare and support for critical care survivors; which is currently lacking.

Post ICU Syndrome is a collective name that has been afforded to the cognitive, physical and psychological manifestations of debility that often faces critical care survivors (Elliot *et al*., 2014). A common means of support for participants once home was through their own family helping them to meet their daily needs. Rattray (2013) pointed out that recovery from critical illness is a worldwide concern that will continue to grow. She identified a significant gap in research related to social aspects of recovery and argued the need for research on social recovery and more on recovery after critical illness in general. A multidisciplinary coordinated recovery and rehabilitation pathway is advocated that begins on admission to critical care through to discharge into the community. In order to best facilitate this pathway it requires those involved having insight into critical care patients' journeys throughout the process.

Survival of critical care in itself can no longer be a marker of success, but needs to be considered within the context of return to an acceptable quality of life (Elliot, 2011, Rattray, 2013). Critical care survivors face a protracted recovery that can take months or years before a return to the health that they held prior to their life threatening illness (Rattray, 2013). Furthermore some may never fully regain the health they might wish to achieve (Ramsey *et al.,* 2012). Recovery and rehabilitation seems to be about facing the limitations associated with admission to critical care,

overcoming those that are feasible and accepting that time may be required to heal or eventually that realistically optimum recovery has been met.

Anniversary: the first anniversary of the critical illness events was pivotal to the psychological mind-set of the participant in their ability to move on with their life and look to the future once again. This anniversary date was like a hurdle to be overcome and a stage at which uncertainty related to their critical illness event changed to represent a regaining of control of their life and planning for the future.

Information pertaining to participants critical illness events is seemingly garnered through a variety of different sources over time and the manner in which participants cope with their illness and associated uncertainty is heavily reliant on family support and their personal satisfaction with their interpretation and acceptance of the information they are given during their recovery period. The development of self-efficacy and exploring the meaning of their critical illness form a fundamental part of their journey to recovery with the anniversary often serving as a pivotal marker for accepting and moving on from their critical illness.

Bench *et al.* (2012) have advocated provision of critical care survivor discharge information in the form of a lay summary. Black & Parahoo (2011) looked at a nurse led family directed critical care survivor psychological support system. While Peris *et al.* (2011) considered a critical care based clinical psychology role. Peskett & Gibb (2009) a critical care sister and ex patient formed ICU Steps, a support group for patients and family. Since their inception they have developed information leaflets for

critical care survivors and the ICU Steps support group has become a regional initiative where other critical care nurses wish to adopt and facilitate their own group.

Some participants suggested that follow-up in conjunction with diary use could help in the recovery process by facilitating closure:

> *"A bit of a follow-up...I think in a sense if they sort of with the diary and meeting up with somebody to talk about things it would give a sense of closure. Closure from certain issues and give people a way forward from it because it's not something that people go through that often." (Clara 6 months)*

The thing that is evident throughout the current study is that most participants found their diary useful, but they wanted it in conjunction with follow-up support. The diary alone provides insight, but not clarification of questions participants may have. Acceptance of what happened and closure were not achieved by all participants for various reasons and follow-up could have facilitated this for those who struggled with their recovery process.

5.6 Summary of chapter

In Recovery: *"Is it normal to feel like this?"* participants asked a lot of questions seeking answers about what happened to them. They questioned how they should feel, seeking reassurance that others have felt that way. They ruminated focusing on

the source of their distress, causes and consequences rather than on solutions (Smith & Alloy, 2009). Rumination and worry are linked to anxiety, panic and depression (Nolen-Hoeksema, 2008). Participants needed coherence about what had happened during their critical illness in order to understand the reality of how ill they had been. Pivotally they expressed needing coherence about the physical and psychological ramifications.

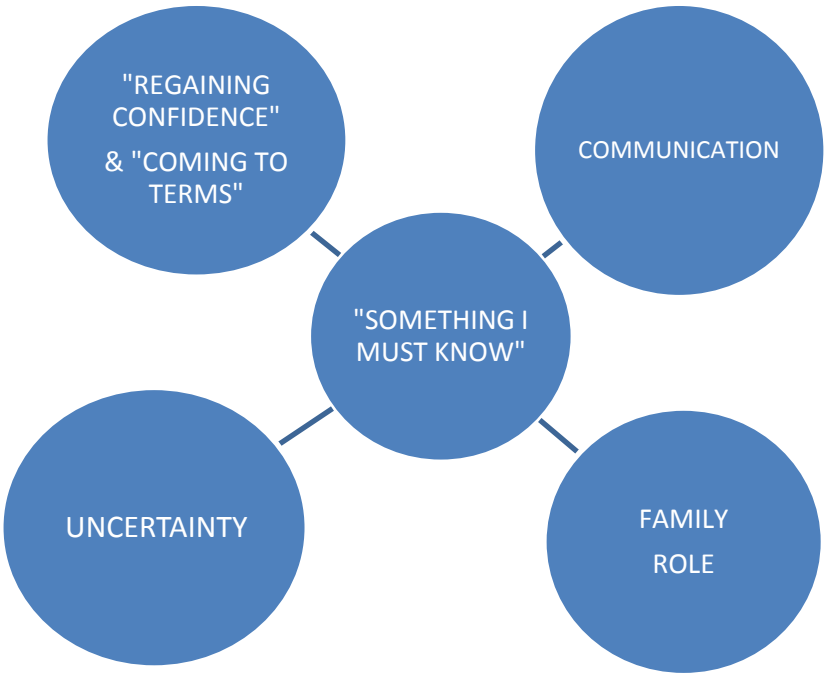
The issues of recovery and impact of healthy or unhealthy rumination and coherence will be explored in chapter 8 as part of the emerging theory.

Chapter 6: “Something I must know”

6.0 Overview of the chapter

The aim of this chapter is to explore participants’ experiences of needing to know what happened to them and to identify the challenges they faced in piecing together a chronological overview of their lives during their “lost days” and developing insight into their ensuing recovery, through realising how ill they had been. It will explore key concepts that emerged from the participants’ experiences of trying to build a chronological picture of what happened to them in critical care from sources available to them. It explores communication, family role, uncertainty, *“regaining confidence”* and *“coming to terms”*, which are key parts of the process for participants as outlined in Figure 9 below.

Figure 9: “Something I must know” and associated concepts



6.1 Communication

A crucial aspect that participants felt was lacking was the provision of information and communication throughout their critical illness journey starting from awakening from their sedation:

> *"I literally couldn't move a thing and I think because that is a constant memory, there is part of me that's sort of thinks, when you come around someone needs to very quickly be able to say to somebody, this has happened to you. So don't panic now we will explain everything to you..." (Clara 2 months)*

Data from the current study demonstrated that *"being out of it",* with *"memory loss"* as a result was a frightening concept for participants to grasp. They expressed a need for information and explanation about what they had been through in critical care. Clara's quote above identified the impact of awakening and she said the inability to move is a lasting memory for her because of the panic she felt. She highlighted that someone should be ready to reassure and explain to the patient what has happened from that point onwards. Interestingly, she felt fear and anxiety until her husband came to support her and try to explain things to her. There is the reality that nurses are busy and do not necessarily have the time to sit and explain things to patients, but this quote highlights the on-going impact of omission of those reassuring conversations.

Participants expressed a need for more information and explanation about what had happened to them after critical care before the transition to home. The not knowing what happened before discharge home was concerning to participants and led to anxiety regarding their ability to regain health and return to normal life routines. There is a desire for truth and honesty and seeking confirmation that comes through from the quote below:

> *"There is just some things that need a little bit of tweaking perhaps, especially for people coming out of intensive care. That are not fully alert then maybe and the understanding of it isn't it of it all, because I think if you understand you deal with it 10 times better, cos not knowing coming out of hospital you were on life support mind and then my husband saying to me one of the consultants came out and said that be prepared to say your goodbyes." (Emily 6 months)*

As noted above the severity of their critical illness was hard to understand when they could not relate to it. Finding out their story from other sources was a pivotal part of coming to terms and acceptance of what happened so they could feel part of something that made little if any sense to them; but was a significant life threatening event.

Participants wanted truthful, factual explanation of events to help them understand their critical illness experience and to help reduce the rumination that unanswered questions tended to produce:

"...I think it would help to understand what you are going through with it, to sort of think you are not going mad. If it had been explained..." (Clara 6 months)

There was almost a sense of loss in terms of knowledge about their critical illness journey and frustrations around the limited insight that they were provided with before discharge home. A common participant need was to be able to talk to someone about the critical illness experience after they had been discharged home:

"...when I first came home things were still going over my head. Things weren't clicking straight away as though I was still sedated, that's how I was feeling really, so I wasn't picking up on things, not as quick...I was more mellow I think, that I, well just as well because I didn't want to worry myself to death either." (Beth 6 months)

While they wanted information, there was also the reality that a one off explanation was not going to work as they often felt bewildered and cognitively lacked the capability of retaining the information.

It is important to be mindful of any harm that could be incurred by sharing information with patients. Some patients may want all the details, while some may not want to know anything at all:

"I'm scared. I have been told some things, but I don't want to know. I don't remember pulling the drips out and things, but I didn't want anything done in the first place, but I would have died of poison otherwise." (Harry 6 months)

This suggests that communicating what has happened to a patient needs to be tailored to each individual. This is a challenging prospect as it is not feasible to offer something that fits with all eventualities.

Whilst some participants would have liked more information to be provided before they left the ward to go home, others preferred the possibility of someone taking you through what happened a few months after the event:

> *"Actually that would have been quite nice perhaps to know a couple of months afterwards when you have got over the shock it would be quite nice for somebody to take you through it." (Clara 6 months)*

It appears that any interventions regarding improving communication, information and explanation for critical care survivors would need to be tailored to a variety of needs. Opportunities and signposting for those seeking more information need to be developed, be that via information leaflets or a ward visit by a critical care nurse involved in their care or a mixture of both:

> *"I don't know whether the nurse, that you'd have somebody come up from intensive care...Well I didn't see anybody then from intensive care. It would have been nice just to have had that, seeing how you were feeling and is everything ok and I got to be honest it wasn't until I come out of hospital, I think it all really started to play on your mind anyway." (Emily 12 months)*

Some participants suggested, as in the quote above, that someone should visit to ascertain their progress once home from hospital. It seems that being told they have been critically ill would imply to participants that someone should check-up and ask them how they are doing:

> *"Sometimes I think there could have been somebody calling on you to see how you are progressing and things like that... I think there could have been someone that come round and asked how you were getting on and how things were..." (Diane 12 months)*

There is a sense that critical illness has been confusing and complicated enough and there is a struggle to understand these events. Participants are confounded by this incomprehension that if they were really that sick would they find themselves abandoned by the healthcare system during their recovery phase of critical illness. There is an issue of fragmented care that is highlighted through the participant experiences shared in the data for the current study. People who have complex care needs also have involvement in multiple settings and HCPs as a result. Transitions between settings and different HCPs can lead to reduced quality of care and care fragmentation (Coleman, 2003). Communication failures are often implicit in such problems (The Picker Institute, 2008).

It is perhaps important then that participants and future patients be allowed to accept or decline offers for information sharing and that they be allowed to initiate the seeking of information at their own pace and readiness. Therefore various opportunities at different timeframes perhaps need to be available during patients'

healthcare journeys. Obviously any strategies that are developed to improve service delivery for patients would need to be mindful of patient choice, resources, time and cost implications.

6.2 Family role

Participants recognised that although they had no recall, their family had witnessed the life threatening events as they occurred:

> "*They (family) had a tougher time than me…well I was out of it…I didn't know anything about it because when I stopped breathing and they called them to get down as fast as…it wasn't very good for them…it was out of my control…" (Beth 2 months)*

A pivotal part of the participants' critical illness journey involved their family members. They were present throughout the events that occurred in critical care but that the participants could not remember. Participants shared that their family support was vital to them:

> *"when I first came home if I needed anything I had close family around me." (Diane 6 months)*

It was important for participants to be discharged with help and support at home, preferably from family members, but as pointed out by Alice, what about people who do not have that option:

> *"I've got my family support see, so I've been fine. I think people on their own, you know, that haven't got the support. I think therefore they should maybe have a health visit on them and you know keep in touch and keep talking…because I have got my family and I have been able to talk it out with them and they've told me their opinions and things like that. So I have had all the support I've needed…" (Alice 12 months)*

Family support, as described by Alice in the quote above meant she felt she was able to talk to them about what happened and she was able to draw on their opinions to support her in coming to terms with what happened. This highlights the concern that, unlike participants in the current study, not all patients would have the social support from close family and friends and consideration needs to be given to how best to help patients who may find themselves isolated and alone facing their recovery process.

Family appear to be left to provide explanation and to support their loved one through the recovery phase (Hazzard *et al.,* 2013). As already mentioned they have witnessed the trauma of the critical illness events and therefore arguably may not be best placed to be the source of this information sharing process that appears to be a crucial step in illness adaptation and recovery.

The study data implied that family absorb the role of *"filling in"* the *"lost days"* for their loved one. This information can be potentially controlled with participants talking about being *"drip fed"* information by their family.

The majority of participants noted that their family *"had a tougher time"* and had been through *"hell"* explaining that this was because they were *"out of it"* and knew nothing about it.

> *"…when you are in intensive care I think it's the families that go through it more than you really because they are seeing it aren't they and living it, while you are just out of it. I think you can't always appreciate it then. I think it is worse for the people that are watching it." (Emily 6 months)*

It is perhaps no surprise that family had their own difficulties to deal with and might not wish to confront the anxiety, fear and stress related to the critical illness, threat to life and survival being in the balance:

> *"...my husband, he doesn't really talk about it...he finds it very difficult the minute he starts talking about it... I feel as if, he've been through it, but in a different way, haven't he? Post stress or something he said he thinks he got...he said it was a stressful, he said I never want to go through that again." (Emily 12 months)*

Supporting this finding Davidson *et al.,* (2012) point out a high incidence of PTSD in relatives finding themselves in this situation. In response to this Hazzard *et al*. (2013)

suggest also giving relatives time to talk through their experience if they are accompanying the patient to follow- up clinic and, if necessary, advise them to seek referral for further support.

There has been a recent interest in critical care family members and development of PTSD with research on this aspect just beginning to develop (Pillai *et al.*, 2010, Krishnaswamy *et al.,* 2014). The impact of witnessing critical illness events of a loved one would certainly form one of the key aspects to be considered for further research from the data provided in the current study.

6.3 Uncertainty

Following their experiences, participants shared the effect that uncertainty had on them during their recovery. This uncertainty appeared to stem from a need to make sense of events.

> *"I think when you are in hospital it's all a little bit frightening as well isn't it? I didn't really know...what was going on and my husband was trying to explain... but whether it could be something that a nurse or something that would come and see you from going into intensive care, coming out into the ward and maybe going through it, because it's not being taken in to hospital on a normal day to day thing is it...it was major and probably half the women in the ward didn't even go through what I'd gone through, but yet you was treated the same." (Emily 12 months)*

Emily said she tried to stay strong for her family and it is clear that she has been deeply affected by her experiences. She desperately wanted to know more about exactly what happened during her *"lost days"* in critical care to try to understand what she went through. She felt confused about how unwell she had actually been and that this was not represented in the care she received on the ward.

Mishel (1988) noted that uncertainty related to unanswered questions can lead to anxiety in relation to a loss of control over the critical illness event, memory of it and what the future holds as a result:

> *"…I don't think I really appreciated just how ill I had been...I think otherwise you would be left with an awful lot of unanswered questions and perhaps then I don't know whether you could ask the hospital to give you answers or what, you know, but I mean I am a distant memory to them now because so many people go through them" (Clara 6 months)*

There is a need for participants to appreciate the reality of how ill they have been. Barriers to this appear to be that their "memory loss" means they do not know what they do not know and as an inpatient they are reliant on HCPs to ensure that they have the necessary information. The study data demonstrate that while HCPs may have explained some things, often the participant struggled to retain and understand what they had been told. A reinforcing of information about their critical illness is needed if the patient wants it. It cannot be assumed that family will communicate everything the patient would like to know, because it has been traumatic for them and they may not wish to relive it.

6.4 “Regaining confidence” and “coming to terms”

Alice was emphatic about finding out what had happened to her while she was critically ill.

> *So, yes, it’s just something that I have got to come to terms with, but it’s something I must know.” (Alice 2 months)*

While Emily felt that she needed more explanation with details that could help her understand what went on:

> *“...it’s hard to come to terms with how ill you were and maybe if that was explained a bit more...Like when that doctor came up to me the first time. It does help, little things like that...I think for me then I could have done with having a few, perhaps the gory details just to have it explained to you...It would have been nice to have somebody to have said...are you coping alright and this is what it will be and you might experience this or...You don’t know do you....you come home and think well is this a normal feeling.” (Emily 2 months)*

The doctor who came up to Emily the first time actually said she was pleased to see her on the ward because when she was with her in the accident and emergency department she did not expect her to survive. Emily felt this was the most honesty she had and that she needed this appreciation of how ill she had been in order to come to terms with it. In other words she is seeking validation of how ill she was. This is supported by Clara, but she had been able to gain a lot of detail about her illness from her husband:

"...I have an absolute zero of recollection...I think if no one had been able to fill it in for me and it's quite frightening…So there are elements and you know with all of it, if you stop and let yourself dwell on it, you can feel a sense of panic from it all, but then I just sort of think...get on with what you can." (Clara 2 months)

There is an implication from some participants that although they seek information, there is an emotional consequence related to trying to understand what happened to them and in trying to come to terms with events. As Clara said in the quote above she tried not to dwell on what happened as that became emotionally draining.

The majority of participants described a loss of confidence in their body and therefore physical health as a result of their critical illness. Ultimately regaining confidence was partly about having knowledge and understanding of what they had been through so that they could feel in control of their own recovery. It was also partly about the recovery time required for their health to improve:

"...my confidence is starting to come back a little bit and my walking is...still not 100% but it's a lot better." (Diane 6 months)

Having the information participants need in order to understand what happened to them is a necessary step in developing confidence in their body again and helping them to coming to terms with their illness, thus being able to move on with their lives as noted by Clara above.

"You have lost confidence in a part of your body and as time went on you begin to think no this is ok...it's been part of it is sort of regaining confidence with my own body and in my mind sort of thinking right what do you do, you either sit here and make yourself an invalid or you run with it and I am not one to just sit and be an invalid." (Clara 12 months)

There is the suggestion that talking about it is a painful process and there may be some avoidance of confronting these feelings:

"It's coming to terms with it isn't it and of course...you don't tend to always bring it up either cos I think it just opens too many wounds and sometimes...it's good to talk, but you don't want to keep on about it all the time..." (Emily 12 months)

Emily experiences a dichotomy, because on the one hand she wants to know what happened for her and not second hand from her family but on the other hand she wants to avoid dwelling on it. This may be true of other patients in that they prefer to avoid confronting what happened to them, preferring not to know. This means that services to support critical care survivors need to be developed with the knowledge that some will access it while others will not. I had hoped to recruit participants who did, and did not want to collect their diary so that I could analyse differences, but was unable to do so. Ultimately the individual needs to feel ready to find out more about what happened, this cannot be imposed, it has to be voluntary.

6.5 Changes over time

At two months participants described a need to harness information from whatever sources were available to them in order to make sense of what had happened to them. This was important to their recovery process.

At six months most participants had the ability to tell a coherent story of their illness and where they had needed their partner to help with the initial story, they did not need them to intervene much for the second interview.

By twelve months most participants felt their illness journey made sense to them. They could recant an overview of everything they had learned and they seemed to own the story which gave them back control and although their interpretation of what happened may not be completely factual or accurate it made sense to them and provided the coherence to their lives that they felt they had lost while they were unconscious and that was missing during their initial recovery.

Information pertaining to participants' critical illness events is seemingly garnered through a variety of different sources over time and the manner in which participants cope with their illness and associated uncertainty is heavily reliant on family support and their personal satisfaction with their interpretation and acceptance of the information they are given during their recovery period. The development of self-efficacy and exploring the meaning of their critical illness form a fundamental part of

their journey to recovery, with the anniversary often serving as a pivotal marker for accepting and moving on from their critical illness.

6.6 Summary of chapter

In Chapter 6: *"something I must know"* participants identified their need to seek answers because communication about what happened to them was lacking. This led to problems in ascertaining a coherent storyline. Most participants were determined to find out and resolve the issues regarding rift in their life, self-identity, loss of control, physical and psychological health: thus needing coherence.

The issues of resolution, communication and needing to know what happened and coherence are explored in chapter 8 as part of the emerging theory.

Chapter 7: Critical care diary: “It’s a piece of jigsaw”

7.0 Overview of the chapter

The aim of this chapter is to explore a longitudinal representation of participants’ perceptions of their critical care diary and analyse what role, if any, a critical care diary has played in participants’ recovery. Their views regarding the diary process in terms of commencement, collection and handover of the diary, therefore the content (type, breadth and depth) and impact are explored at two, six and twelve month stages of their recovery. The potential benefits or harmful aspects that could pertain to diary use are considered. The coding of the conceptual category is outlined in Figure 10 below and these are used as subheadings throughout this chapter.

Figure 10: Conceptual category Critical care diary: “it’s a piece of jigsaw” and associated concepts

7.1 The diary process

7.1.1 Collecting the diary

The invitation to collect their diary arrived without an explanation about what this entailed, thus evoking anxiety for Emily:

> *Researcher: "Do you have any memory of intensive care?"*
>
> *Emily: "I didn't want to go back in there and I didn't want to face it" (Emily 2 months)*

Emily felt uncertain about what was expected of her when collecting her diary and this added potentially unnecessary emotional burden for her. Collecting her diary impacted on Emily throughout her recovery and she pointed out at six and twelve months the diary was not really something she would have wanted for herself:

> *"…he (husband) said are you going to go back for your diary and I went oh no, because I think I thought to myself I don't want to know anything that was going on. What do I want to know for? Forget it now…it happened and no I don't really want to know…" (Emily 6 months)*

Emily obviously would have preferred to cope by not knowing what happened and the diary process was overwhelming to her and potentially hindered her recovery rather than helped it:

"... I was a nightmare the morning, going down for the diary, cos I get myself so worked up, that I am really so anxious. I'm biting everybody's head off... because I'm get so... because there was nothing at all in hospital, nothing." (Emily 12 months)

Clearly Emily was very anxious on the day she had to collect her diary and it was a stressor for her because she had not really felt she wanted her diary. The quotes represent a year in Emily's recovery where collecting her diary still troubled her. This highlights that careful consideration is required about the manner in which the diary is offered to patients. A need is indicated for supportive information about the purpose of the diary and how and where (neutral environment, not critical care) it will be handed over, with time for discussion and clarification being offered.

Despite Emily's hesitancy to collect her diary the majority of participants wanted to collect their diary and in most cases it was essential for them to find out more about what happened to them. Alice had not been to collect her diary at the time of the first interview and she clearly found the idea necessary, but emotional:

"I felt a bit weepy (became emotional and cried a little), which I most probably will when I get my diary 'cos they've all (family) said to me about crying and I haven't cried (cries)…it's just something I gotta do (emotional). I think I am only just realising how ill I was" (Alice 2 months)

Alice had not yet collected her diary and talking about it at interview she became emotional and had a cry. In verbalising her story she said it was the first time she

had realised how ill she had actually been. She found it useful to acknowledge this and to have that recognition by participating in the study seemed to help her. Interestingly participants concurred that when they collected their diary they were invited to see the unit, but nor given opportunity to sit down with the diary team and discuss their diary.

> *"I did say it is hard to understand and they did ask me if I remembered anything there and I said no. Only when I went in I was shocked at the bright lights and it was always dark…they said I must have been waking up in the night; that would explain that." (Alice 6 months)*

Alice, unlike Emily, was not put off by seeing the critical care, but she was quite shocked by the experience. This emphasises the point that expecting critical care survivors to come to the environment where they were life threatening ill, and which they do not recall, is too much too soon.

> *"Yes the diary is good, but I think there should have been a little bit more information in it. They are so busy there I think they would have been more interested in taking care of you than writing in the diary. I know there was one nurse there who looked after me a lot and he never wrote in there." (Alice 12 months)*

Wanting more information about what happened is evident in both Emily's and Alice's quotes at twelve months.

It is possible that not every person would want to have an in-depth conversation at the point where they collect their diary, but consideration needs to be given to how best to share the diary with the patient and meeting their individual needs.

> *"They didn't go through the diary with me…I said the thing is I haven't got any questions because I was out of it. So they said I could phone up at any time with anything I wanted to know and just have a talk, but I think it is self-explanatory…The only rude awakening was what *(the nurse) wrote the one night when things were not looking too good." (Beth 2 months)*

Although Beth did not feel she had any questions when she collected the diary, she did after reading it and the fact that she knew how busy the critical care unit was meant she did not feel it was appropriate for her to ring them.

> *"Basically what I have learnt, he (husband) hasn't told me all that much, but my daughter has, because I stopped breathing and they had to resuscitate me. I didn't have a heart attack or anything like that." (Beth 2 months)*

Beth confessed like most participants that as soon as she got home with her diary she read it immediately on her own. She was shocked to read that she had almost died in her diary. It was clear during the interview that her husband had not wanted her to know and that her daughter had discussed what happened further with her once the diary had been read and prompted questions. However, when Beth showed the diary it clearly stated she had a "PEA arrest", but the term meant nothing to Beth

and there was no critical care follow-up opportunity to clarify facts with her about key events.

7.1.2 Handover

The purpose of a face to face diary handover is to facilitate an open discussion, guide through the diary content and enable questions to be answered and clarified; avoiding reading the diary alone (Jones, 2009a). In the study setting the diary handover was not a run through of the diary or a discussion based meeting. Instead the diary was handed over after the invitation to look around critical care; like an after-thought.

A risk in allowing participants to return home to read their diary without a facilitated handover process is that they have potential to read emotive information unsupported and alone. There is no opportunity to clarify or discuss content or how they feel about it:

> *"They said read the diary a little at a time, but no I couldn't do that could I. So when I came home I sat in the front room and read the whole thing. I finished it. So maybe that was a bit of a mistake, because it was a bit of a shock. I didn't get upset, because I was out of it." (Beth 2 months)*

All participants were handed their diary on the way out; to be read at home. A visit inside the critical care unit seemed to take precedent over the handover process:

> *Researcher: "When they gave you the diary did she go through it with you?"*
>
> *Diane: "Well she took me into the ICU and you see a lot of the machinery in there, the breathing apparatus." (Diane 2 months)*

By taking participants in to look at the unit the diary team seemed to be using that rather than the diary as an opportunity to talk about what happened in critical care:

> *"I think it was nice knowing sort of like what...equipment you were on and what they actually did to you while you was there...helping to breathe, all the tubes which were feeding me. I had to have blood in to my body...that they was fighting for my life as well and helping me all they can...I wouldn't be here if it wasn't for me going in there. I think it was an eye opener to see..." (Diane 6 months)*

The literature available about critical care diary use suggests that the diary is usually read to the patient by the nurse at the handover, which occurs at a follow-up appointment (Egerod *et al.,* 2013, Nydahl *et al.,* 2014).

Ewens *et al.* (2014b) had professionally printed diaries produced for their study. Their approach to the diary handover was different to that previously described in the literature (Åkerman *et al.,* 2010, Gjengedal *et al.*, 2010, Egerod *et al*., 2011b). The

primary researcher would visit the critical care survivor just prior to their transfer from ICU to the ward and talk them through the purpose and content of their diary. A researcher would continue to visit every two to three days to answer any questions that the patient may have about their diary. There was provision of support should any patient require it after reading their diary.

7.1.3 Reading the diary

Participant data identified that, because common practice in the study site was to wait 48 hours prior to commencing the critical care diary, their diary omitted the first few dates when they were potentially most unwell and this was a source of concern.

> *"Those two days that were missing, that was the one day that my grandson actually came in with my daughter. It doesn't say about him being there." (Alice 2 months)*

Without explanation some participants were left with unanswered questions, as with Emily in the quote below. Emily and her husband had searched the internet for information, but this resulted in more anxiety and questioning about her illness.

> *"…they said I had pneumonia, but when my husband read on the internet, there are so many different types of pneumonia. I don't know what type I had. Will it come back again? Am I going to have weakness there? It would have been nice to have that explained to you." (Emily 2 months)*

7.1.4 Photographs

All participants were told there would be a photograph as part of their diary. However, only three actually received their photograph. Failing to provide a photograph as promised was a source of further conflict in achieving coherence and making sense of the reality of what had happened for participants.

> *"I think if there had been a photograph then maybe you could think blinking heck…I think the diary is a good thing, but I do think intensive care needs to be able to be explained more then. It is not just a normal ward, it's not, and the things that happen in there…like I didn't realise that I was on life support." (Emily 2 months)*

Emily's husband had tried to draw a picture to explain all the tubes that she had during her time in critical care and it just did not make sense to her.

Having a photograph in conjunction with the written elements of the diary was a means of reinforcing the care that participants received, but also about aiding in explaining things to them. Seeing the photograph gave those participants who received one further visual confirmation of how ill they had been: the reality:

> *"She asked me did I want to see the photo. She said if you don't you can see it when you go home, in your own time. My sisters were there, they came down with me because they wanted to see the girls and show their*

appreciation. They said go on have a look at it. They had seen me in the bed with all these tubes and the machinery. I did have a look. I felt a little bit tearful...Looking at the photograph I thought oh my goodness. If it wasn't for ICU I wouldn't be here." (Diane 2 months)

When photographs were available it did enable participants to ask questions about their appearance, and as demonstrated above, to gain answers and even some insight in to the reality of how critically unwell they were. Diane's photograph acted to validate or confirm her critical illness:

"With the colouring that I had in the photo I thought my blood pressure would be really high. Do you know it's very very low! They obviously treated me for that…I look at that and think well I might not have been here now. When I look at that I think that is not me, but obviously it was me." (Diane 2 months)

Interestingly, for some participants the need to have a photograph increased over time and, as Alice explained below, this was because she wanted to visualise it for herself rather than just hearing about it from family or reading the diary content. So Alice has been left without the validation or confirmation of a photograph demonstrating the reality of her illness to her:

"The only thing was; I was hoping that they had the photo and they said they had lost it...everybody tells me about it and what I was like. I just want to see for myself I think. It's just another part of it, sort of thing, you know.

Disappointed, yes, I was expecting a photograph. They told me about it and I was prepared for it." (Alice 6 months)

When there was no photograph, participants felt it left a void in the story of their critical illness journey. Possibly the visual nature of a photograph being able to capture more than words can say, but also making it a reality by actually seeing themselves, rather than just hearing it from family and trying to use their imagination. Having a photograph has potential to add to the coherence of the illness story for participants.

Furthermore, a photograph had the potential to provide reassurance about the care they received:

"I think the photo shows you how you were respected, how you were covered up, you were in a clean bed…So I think it does reinforce part of your care…I think it also helps to know why, for instance, I have got scars here on my neck…besides where the trache was…I think that when you first see all your scarring, you can think oh my God what the hell were they doing, whereas the picture explains it…the little feather scars Ive got is where the trache was put in place…it just helps with the explanation of where you went with it." (Clara 12 months)

Data from the current study support the fact that participants felt unprepared for the enormity of impact that critical illness had on their ability to recover. It also highlights the impact that *"being out of it"*, *"lost days"* and *"memory loss"* had on participants. The use of a diary was beneficial in most participants' experience; it aided their

knowledge and understanding about what had happened to them so that they could start to understand why they were left with psychological and physical consequences to overcome.

7.2 Being ready to know

Participants' experiences in the current study identified that some would not have been ready to face this discussion about their diary while in the initial stages of trying to comprehend what they had been through, while for others it may have helped.

> *"I wasn't really going to go and pick it up and part of me didn't want to go down that road. So I have only read little bits of it." (Emily 2 months)*

Similarly Clara was not sure she would collect or read her diary.

> *"I don't know that I am strong enough yet to have the harsh realities in front of me." (Clara 2 months*

There is difficulty attached to providing a diary approach that works on an individualised basis as no one approach will work for all and the challenge is how to facilitate critical care survivor needs in a multifactorial manner, while keeping time and resources to a minimum. Emily was still hesitant to read her diary properly at six months.

"I was out of it, but it's nice to look back, haven't really gone into it, just flicked through it." (Emily 6 months)

Clara was different in that although she was concerned about being ready to read her diary, once she had it she found it helped in her coherence of what happened and realisation she had been in shock. Appreciating this aided her ability to recover.

"I was still in shock I think as to what had happened to me…But I do think that diary is fantastic…" (Clara 6 months)

Some participants did not look around the critical care unit when they collected their diary because they were not ready to do so. Emily still struggled with the idea of this a year later.

"I am quite a shy person and I don't know whether I'd cope with going in to a room full of people...I would find that all too much. I couldn't walk into a room and like nurses that looked after me I would find that really awful. I didn't want to go back...but like in a few years' time I might be sorry that I haven't gone in, but it's how you feel at the time isn't it." (Emily 12 months)

In the case of Clara she had moved onwards in her recovery. Emily seems to have remained static in her recovery process.

"It's made me appreciate life. It hasn't come without its ups and downs….I think I have come out stronger from it. I am just grateful to be here." (Clara 12 months)

Prompting recall of the participant time in critical care should be handled with care as their psychological capacity to deal with such confrontation would not be able to be adequately assessed by the diary team member showing them around and it is evident that no debrief is provided (Toien *et al.,* 2010). In reality the current diary handover process, in the study setting, is like a one off debrief which is criticised in the literature (Mayou *et al.,* 2000, Litz, 2008). According to Bisson *et al.* (2013) support for individuals following traumatic events needs to form a series of supportive sessions.

7.3 Capturing what happened

Participants' recovery following critical illness was described by them as a quest to piece together the jigsaw that comprised their critical illness story and the importance of knowing what happened:

> *"It's a piece of jigsaw I suppose and there is going to be pieces missing from that time, but I think it would be nice to look at what happened and when it happened and why it happened...that's the bit where the diary could help out…I suppose you do feel that you have lost that part of your life… So it would be nice to know what was going on... (Graham 2 months)*

The participants' experiences demonstrated that there is a need in some cases for an open and honest overview of all events that occurred to be provided.

"So I am still finding out bits and pieces you know." (Beth 6 months)

In the case of the participant quote above, she knew her family were holding back information from her about what had happened. While they were trying to protect her from knowing that she had almost died, she needed to know the truth in order to form her own coherent critical illness story to resolve the rift it had left in her normally continuous life story.

Participants raised the point that it is important HCPs do not assume patients know what has happened, even if they have been told more than once:

> *"I think the one thing is... for people not to assume that what you have told the person has gone in, because it certainly hadn't with me...it could just be a black hole and some people may not ask...I think that the diary is a way of doing it and helping someone and supporting them then as they get back to normal." (Clara 6 months)*

So the diary can act as a way of coming to terms with what happened and facilitating recovery, by enabling the rift in their life story to be repaired through chronicling their missing time. Provision of a diary can hand back control to the individual it was written for, as long as it contains enough detail and explanation about the significant events that took place.

Knowing what happened to them and reaching a point of acceptance seems dependent on the information, communication and explanation that is provided and of which the critical care diary is a part of a process of assimilation:

> *"I never questioned anything and that's not my nature and I do sort of think I was in shock. You know coming round from it all and everything with it and I found my diary and I did read another piece, I have read it and I cannot say how much that diary is meaning. The biggest disappointment for me is that it didn't continue...because I have got that chunk missing and although it's not something you want to dwell on...if you hadn't had the family support that I had…I think it is something that really really is valuable." (Clara 12 months)*

The diary seemed to reduce participants' sense of detachment from their critical illness event and in most cases they expressed better comprehension and insight. The diary alongside other sources of information, such as family, seemed to help participants in forming new foundations of memories and creating their own story. They could then incorporate this into their life story narrative; as long as family felt able to be honest.

Participants shared a desire to piece together a chronological timeline of their critical illness journey. Collecting information through reading their diary and talking to family was pivotal in helping them to integrate their missing days.

> *"I suppose that's the only thing I felt and as far as the diary is concerned it would be nice to have a fuller story. So when you come to read it, you may*

not be happy reading it, but at least it puts... pieces of jigsaw together so you have a bigger picture." (Graham 2 months)

A diary can enable clarification of the timeline of the critical illness journey and provision of a chronological overview is identified as important in the literature. According to Nydahl *et al.* (2010) patients who have spent time sedated and ventilated in critical care often want to reflect back on their experience. Reconstructing a coherent chronological picture of their lives, which have been disrupted by their critical illness, was a vital part of needing to know what happened. Åkerman *et al.* (2013) study concurs by identifying that patients need as much information pertaining to their critical illness as possible, but in a chronological manner as this helps them to construct a story for their missing time.

Participants indicated that dates in their diary were important because they helped in knowing what happened for the days that they could not remember due to their *"memory loss".* The diary acted for participants as a provider of 'proof' that they were critically ill, giving them a sense of reality of what occurred during the missing time. Therefore providing reassurance by removing the uncertainty aligned to the memory gaps left behind from their critical care admission.

"The diary told me where I was for 10 (days). I had written proof of where I was...Well I knew how many days I was in hospital because the diary told me so many...So then of course it all clicked in then the 4 days were prior to going to ICU. Then that gives you peace of mind knowing, that's fixed that little problem. At least you know what's happened and I think that's important." (Beth 6 months)

It was difficult for some participants to connect with their lost days and if the diary was brief, as the case below, it did not always resolve this issue:

> *"I think that's when it hits home...we were talking about something the other day and from about * until about the *, it just didn't exist, those dates and that's quite a weird feeling mind to look back in the diary and think there is nothing." (Emily 6 months)*

Another participant concern with diary use is that at present it is not continued when a patient is transferred to another Health Board:

> *"I felt very, like I said when I got to the end I just thought, oh I don't know now, I don't know the rest of it. You know much as my husband and my sister had filled in as much as they could. You just sort of think hang on there is 4 weeks still missing now. So I think what you've created there is absolutely fantastic." (Clara 6 months)*

Those participants who were transferred for specialist care were left with missing time in their critical illness story. The quote below highlights that the consequence of the diary not continuing with them was that the diary lacked the ability to help them piece together the jigsaw of what happened, so they were left with a disrupted picture and their lost time remained incomplete:

*"I think what would have been handy if this diary had been passed on to the *(specialist hospital) and then you know perhaps bits of the jigsaw would fit. Yeah so it would have been nice to look back on that and see, but it was only the period that I was at the * (local hospital)." (Graham 6 months)*

When the critical care diary failed to cover what participants construed as their *"lost days"*, it left them with a lack of coherence and therefore control over their lives:

"The only thing is there are 2 pages missing. There are 2 pages where they haven't written anything. I think that is where I was so ill, the 2 days after the operation there was nothing put in there. It did say after the operation I had taken a turn for the worse and the family was called and then 2 days then there was nothing wrote in there and then it picked up again...Even if it said...that I wasn't improving or...some sort of information." (Alice 6 months)

The impact on memory affected all participants and they all found the missing time hard to comprehend. However, having their diary to read did enable them to build a relationship with the dates they could not remember:

"I can refer back to the days now, you know, when I was in there…telling me how bad I was and what the family was doing."(Alice 12 months)

Part of the criteria for commencing a diary was that it would start after 48 hours and this seems to be the source of Alice's missing dates and the impact of this needs to be considered. It is possible that the diary should start immediately to ensure the

most critical days are included. Resistance to this may be that not all patients require longer term ventilation, but data from the current study indicates that regardless of length of time sedated and ventilated, it is the *"lost days"* and *"being out of it*" that need to be addressed for patients so that they can re-establish their missing life story timeline to gain coherence and self-identity.

The interpretation of their story through their diary and family is pivotal to help participants integrate their missing days and time that form a part of the continuum of their life. This would help to redress the imbalance caused by not knowing and reduce the uncertainty they feel. This could aid in a regaining of control over this life threatening event of which they do not feel a part. It could enable clarification of the timeline of the critical illness journey as provision of a chronological overview is identified as important in the literature. According to the literature, a way of facilitating this reflection is to have a chronological record of events via the provision of a diary, with a follow-up appointment that enables discussion and questions to be answered (Båckman & Walther, 2001, Combe, 2005, Åkerman *et al.*, 2010). The diary may not always provide enough information; in this case it covered only a brief admission and not the second admission period, although they occurred in the same month:

> *"…although those dates are in that diary, they still don't mean anything mind because those days, as far as I am concerned just never existed and won't exist now. I suppose in some ways that's knowing what you have gone through, but not really, it's not enough, for somebody to have been out for 5 days and then waking up on a ward..." (Emily 6 months)*

The diary can act as a resource to look back at dates and to provide additional information that participants can use to construct their interpretation of their critical illness story and gain coherence about their missing time:

> *"...that's just filling in the gaps of when I wasn't with it so to speak, because your memories are there, they are made when you are awake and you can file that away, but you know, it's that black hole of when you weren't with life…it gives you an overview of the story, but without going too technical with it and it genuinely shows you that the staff and relatives writing in it and all are pitched at the right level…What to me it is doing is just giving me a day by day account..." (Clara 12 months)*

Generally there was consensus by participants that their diary was helpful in providing explanation of their missing time, in conjunction with family discussion:

> *"...My 10 missing days as I call them, which they are not so missing now; which I am thankful for...and with the little bits that they tell me [family]..." (Alice 12 months)*

Capturing the missing time enabled participants to interpret their story in their own way and to use this to tell their story in their own words to others and eventually to feel that the rift in their life story was healing. In finding out what happened they were able to reduce the uncertainty they felt and regain a sense of control over this life threatening event of which they do not feel a part:

"I just think people are being given the opportunity to see something and partly experience something that at the time they had no knowledge of and for some people it's important that they understand the journey they have been through… all round for me, everyone that wrote in there played a very, very important part in my journey."(Clara 12 months)

As Clara explained, knowledge about what has actually happened to her has enabled her to understand her critical illness journey. Initially at the two month interview she was unsure if she felt ready to collect her diary and if she would bother. At the six month interview she said she did not know why she had been so worried and that it had been helpful to her recovery because she was beginning to understand what she had been through and was relating that trauma to how her body was reacting during her recovery. At the twelve month interview Clara explained how the diary has acted as a vehicle for her to gain some understanding of her critical illness, that at the time she felt she was not a part of because she was unconscious. This is further supported by Beth:

Researcher: "What has the diary offered to you do you think?"

Beth: "Peace of mind in a way. That's something I know nothing about, that I could be part of it afterwards. Instead of being ignorant of what has happened while I was out of it for 10 days… Well you feel more in control, not so out of it…It's hard to explain. It's comforting. I found the diary comforting." (Beth 12 months)

It is these pivotal statements by Beth and Clara that sum up the role their diary has played for them in regaining a sense of control over events because it enabled them

to gain coherence about events. Ultimately it has given some participants a different perspective of events to that provided by family and in some cases it facilitated participants' understanding of what went on; enabling them to feel part of something that without the diary they did not. However, in Emily's case it did none of this; leaving her ruminating about what actually happened.

Through reading the diary, for some participants it provided pieces of information, usually chronologically, that they could use to appreciate how ill they were:

> *Researcher: "So how did you feel reading the diary?"*
>
> *Graham: "I realised what went on then…and what really happened I suppose for that short period of time. That's why I think it is important that the diary that the diary should go with you so you get a full picture, because, you know, that was there, but then I spent more time in the * (specialist hospital)…so I don't know what happened in the * (specialist hospital)." (Graham 12 months)*

Clearly the diary had been useful for Graham in capturing the initial part of his illness journey, but it did not provide a full picture of what went on because Graham was transferred for specialist care and the diary stopped at that point. Participants suggested that the diary should continue with them, or a new diary be started to capture as much of what happened to them as possible.

However, for Emily the diary did not tell her anything she felt was important to know and she was left not knowing whether all that her husband told her was true or

exaggerated. She also expressed concern about not knowing how she should feel and what was normal after critical illness. She wanted permission to feel the way she did. She shared feeling guilt about her avoidance of the symptoms she was having and being a fraud for feeling so detached from things even on returning home. She did not feel family appreciated how she felt and she knew they had been through an awful time so she seemed to try to hide her true anxiety and fears.

7.4 Constructing the critical illness story

The quote below identifies that some relatives wanted to protect their loved one from the traumatic events that they had been privy to.

> *"I didn't have it until January! (In response to husband saying he wouldn't have given it her until then) It's my diary, not yours! I know you had to sign for them to have permission to do it." (Beth 12 months)*

The addition of family views and experiences added to the meaning of the diary and their critical illness for participants:

> *"I didn't expect to collapse and how I was so ill I suppose and because there is a month out of my life that I have got no recollection of, which did bother me, but now I thought well, I can't get it back, I can't remember it, that's it. Draw a line under it and the family have filled me in on what happened as I say and then the diary has filled me in on some of that time as well." (Alice 12 months)*

Bergbom & Askwall (2000) and McKinley *et al*. (2002) found that family are a vital source of security, support and reassurance for the patient. In the context of the participants in the current study they all had supportive close family to help them through their critical illness journey. The psychosocial dynamics differ for critical care survivors and that needs to be borne in mind when offering them a diary without on-going support in place.

Study data indicated that following critical illness there seems to be a reliance on relatives to fill in information. Given the traumatic nature of the life threatening event that they witnessed, it could be argued they are not necessarily the best source of information for critical care patients. Expecting family to revisit traumatic experiences could be detrimental to their health and well-being (Toien *et al.,* 2010, Bisson et al., 2013). Information provided by family may be inaccurate and selective. This emphasises the need for follow-up support, not only for the patient, but also for family as well:

> *"I think it would be quite nice for my husband to have a chat with somebody...for him maybe to understand how I feel, does that make sense? Because he would see... people who have been through it; it is totally different needs, but it would be nice for him to meet somebody else that have been in intensive care and to know what I am feeling... but I can't even begin to imagine if I had to go through it...like when you are in intensive care it is touch and go isn't it?...I can't even imagine." (Emily 12 months)*

Family witnessed critical illness potentially forms a barrier to effective disclosure of the reality of events that occurred. Family may not want to relive what they went through and participants clearly picked up on this. Family experience could form an additional burden to their own complex situation of being a critical care survivor and trying to establish what would be normal to expect in their situation. Furthermore, because there is no follow-up process, people are being left to cope alone once they leave the support of the healthcare system and go home.

Concern about the impact on close family members of admission of a loved one to critical care has recently become an aspect of interest in adult critical care research, with Jones *et al.* (2012) conducting an observational pilot study RCT to explore intensive care diaries and relatives' symptoms of PTSD. According to Garrouste-Orgeas *et al.* (2012) and Jones *et al.* (2012) use of critical care diaries had a positive effect on critical care survivors and their close family by acting to reduce anxiety and symptoms of PTSD.

The diary can form a means for relatives to let their loved one know about the critical illness events from their perspective, in conjunction with nurses and other HCPs entries. This quote demonstrates that the diary provides an overview of daily life whilst the participant was unconscious:

> *"They wrote in the diary every day who was there and what I was doing...It was a hard time for my family as well as myself! I got there in the end." (Diane 2 months)*

Ewens *et al.* (2014b) said that patient diaries are a way of enabling a connection between the patient and loved ones during their missing time. In the quote above, the participant has been able to read the diary and gain insight into how her illness impacted on her family. One participant pointed out that she felt the diary offered her family emotional release because they could express how they were feeling in it:

> *"I think its twofold for me; it was a way of them expressing and telling me how they felt, but I think for them as well it was a way of them putting down some of that feeling perhaps dumping some of the stuff that was perhaps going around in their mind, because I said to my husband, I can't imagine what he went through..." (Clara 6 months)*

The diary can form a part of the reorientation process that occurs through family discussion by providing information written at the time it occurred and arguably this is more reliable than second hand information from the family (Ewens *et al*., 2014b). Family provided one source of information about care participants received, but there was a need to have written confirmation of this through reading the diary:

> *"The family has told me so much that went on, but yes it was nice to read, to have it on paper, to read it myself and I have got it and I am keeping it, that sort of thing." (Alice 6 months)*

The family role is centred on emotional support, but it is also about information and helping the patient to understand this stressful event and to provide support. It is

clear that in some cases family felt unable to share how traumatic the critical illness situation had been with their loved one:

> *"I was quite calm and especially after I had the diary. It answered a lot of, but no I wasn't unduly worried no...Well I had some answers, but as I said I knew they (family) were not telling me everything...I couldn't rely on them to tell me everything, could I? They were just giving me little bits and pieces" (Beth 12 months)*

So in some instances the diary can take pressure off families when it comes to explaining what happened.

The current study data suggest that validation or confirmation was required by participants and the quote below shows how a diary can provide some comfort and control for the participant:

> *"Well the diary doesn't say anything about where you had all the tubes coming in and out of you, but my daughter has told me...but you don't feel quite so helpless. It keeps you comforted somehow knowing that somebody cared enough to write in the diary when I knew nothing about it. My husband and daughter are not always in the right frame of mind and all that going on to remember everything… I enjoyed reading it. Apart from that one where things were a bit dodgy. It sort of kept me in the loop, that's how I look at it. I'm glad they kept a diary; I think it's a marvellous idea" (Beth 2 months)*

Beth felt she needed to find out what had happened and could not wait to collect her diary. Her family had not told her how ill she had been. While this participant had indicated she could not wait to read her diary and did so as soon as she got home, it did upset her. Provision of support and time spent discussing the diary in her moment of realisation that she almost died would, perhaps, have been a better approach.

Fran found it very emotive reading her diary and explained that she had not yet been able to read everything that her husband had written:

> *"My daughter had written somewhere about my grandson. Oh I can't remember what she said now and yes reading that afterwards and every time my husband has written in here, he is putting…so and so rang very upset. Yes so it was all things from home were still there…" (Fran 2 months)*

She told me that her diary was in a safe place and she knew she could access it if she wanted to. This was a common comment during interviews, with participants saying that their diary was important to them and valuable enough that they kept it safe and accessible to them. Participants seemed to be prompted to access their diary if they had a bad day, if friends or family were visiting who had not seen it and if there was something that triggered them to think about it, such as something on television, in the paper, or approaching the first anniversary of their admission.

The emotional impact of having the diary, reading it and trying to digest it cannot be ignored. Furthermore, if the diary content does not suffice, it appears in Emily's case to have resulted in rumination about what went on because she lacks the answers she is seeking. Some supportive measures beyond a one off contact to handover the diary seems a logical step to help critical care survivor's psychological health and well-being, which in turn can impact positively or negatively on their physical recovery and rehabilitation process.

> *"Although the doctors haven't written in there I am aware of the doctors telling me what was going on all the time. I mean if I asked questions I remember I was answered."(Alice 6 months)*

In the study site it was mainly nurses who made diary entries, with one or two physiotherapists or dieticians occasionally making entries about plans and progress. Perhaps a more integrated multi-disciplinary diary approach is required with shared training, guideline development and adaptation of the diary to facilitate this:

> *"Even my physiotherapist put one in, bit in there the one day." (Fran 6 months)*

Literature suggests that nurses tend to be the main contributor to diaries (Jones, 2009a, Gjengedal *et al.,* 2010).

> *Researcher: "How did you feel about the way the nurses have written?"*

Graham: "Oh I think that's fine, I mean that's all part and parcel of a diary isn't it. At least it gives you a balanced view of what was happening, you know. If it had just been the family writing in there then I wouldn't really have known what was going on I suppose. You know what they were doing medically." (Graham 6 months)

Participants valued the nurses contribution to their diary as providing a more detailed and potentially factual overview of what happened to them. Additionally, reading the nurses' comments about the time over which they had no control was comforting and demonstrated to participants that they were well looked after:

Researcher: "So do you think there is anything in relation to the diary that you think could be done to improve it at all?"

Beth: "Not really no, because the person that writes in it is the person that's the person that's looked after you for the 12 hours and they are not going to write down every time you move in bed or you know what I mean. It tells you enough to give you comfort and I find that very comforting." (Beth 6 months)

In some ways the diary helped the participant to develop a sense of a nurse patient relationship that normally occurs in hospital, but in this case it was a retrospective narrative story provided in a personal manner by each nurse involved in their care:

"I find it quite fascinating, to me it's quite enjoyable reading because it's written in such a one to one personal way and then there's like, take care, you know, you had a good night, I have been looking after you all night and stuff

and so you get this cocoon effect and that's what I had when I was in hospital, I was cocooned." (Ian 12 months)

As participants referred to their critical illness period as a time they cannot remember, the diary seems to have a role in facilitating their sense of relationship not only with that lost time, but also with nurses who they previously perceived as strangers:

Researcher: "How does it feel reading that sort of thing and the way they have written it?" Diane: "Obviously you can tell that they were looking after me." (Diane 2 months)

Family contribution to the diary was more about the normality of what was going on at home, or the weather. This played a different role in the diary for participants. Family entries in their diary showed they were loved and missed while they were unconscious:

"It was nice to read that when I was ill who was there. Some of it I could smile at when they were writing, when they were writing rainy day and smiley face or a miserable face...it is nice then that they could see me making progress. In the beginning you read it and it sounded a little bit dowdy. As you go through it you can tell they were happier to see me making progress and obviously the nurses as well." (Diane 2 months)

A recent study described discouraging diary entries about ‘meaningless things like the weather’ (Ewens *et al.,* 2014b, p.30). However as the participant quote above suggests, most participants in the current study liked things such as comments on the weather, construing it as a symbol of normality during the time they could not remember.

Participants in the current study felt great appreciation to still be alive following the care they received and concurred with Ewens *et al.* (2014b) study where participants felt cared for and grateful that nurses took the time to construct a diary for them:

> *“I had brilliant support from ICU, support from my family and just be reading that (diary) you realise what they actually did for you. I just appreciate everything that they have done for me and without them I wouldn’t have been here today.” (Diane 2 months)*

One participant pointed out that she could compare the concept of having a diary to not having one, because she had a diary kept for her initial admission, but not when she was transferred for specialist care:

> *“If I hadn’t had it then actually I can compare this can’t I? Because the two weeks or so that I was in the * (local hospital) I have got it and the four weeks down the * (specialist hospital) I haven’t got it and for the two weeks that I was in the * (local hospital) they are telling me day by day what was happening, a rough idea and it was nice, lovely when the nurse has put in there ‘we don’t know what the future holds’ and it actually makes you think I was really cared*

*for...well I know I was down the * (specialist hospital), but the nurses haven't had the opportunity to put it into words there. So for me, not having it left a big black hole. Having it certainly filled in some of the gaps for me..." (Clara 12 months)*

Clara pointed out that for the initial part of her admission to critical care she had a diary. This provided her with some insight about what was happening day by day. She does not have this for the specialist hospital part of her journey. It seems that having the diary provided chronological information and also provided reassurance about her care through the nurse's entries.

The personal nature of the diary entries and how genuine the nurses appeared through what they wrote came across to participants:

"…I don't know how the staff feel about it, but certainly for me the genuiness…it's not just a job they turn up for; they are living this journey with you and they have played an important role in it. For them to be able to express that as well, it's nice and to relieve some of the pressure that they must feel...I know they deal with you, even when you are asleep, as a person by name they call you, they talk to you, but to actually go on record saying things I would imagine it's quite nice, for them as well..." (Clara 12 months)

Sustainability of diaries is reliant on diary team function, with research suggesting that the lead nurse for the diary team usually acts as the sustaining force by

continuing to promote diary use and encourage staff to participate in the process (Jones, 2009a, Akerman *et al.,* 2010, Gjengedal *et al.,* 2010).

> *"The nurses have said what I done that day and they have taken this out or when they put that in or you are going to have a tracheotomy tomorrow…which I think is good because you know how far along you have had them done… If it wasn't for that I didn't realise I was in hospital for a week before I went up there (to critical care)." (Fran 2 months)*

Her diary was able to provide Fran with a timeline of key things that happened, in a manner that made sense to her. In some situations the timeline of the critical illness journey was disrupted due to transfer for specialist treatment.

> *"I would expect it to contain everything warts and all if you like, because it is part of life…I am assuming it's going to be things like that in there you know, with the dates, but of course I was transferred…they are pieces of the jigsaw over that period of time…There are going to be pieces missing…Yes even for your personal satisfaction that this happened on that day, that happened on that day and if the diary had gone to the (specialist hospital)…I think there is some merit in perhaps having an agreement between hospitals…if you have to move that the diary goes with you." (Graham 2 months)*

Graham had not collected his diary by the two month interview, not because he had not wanted too, but that the invitation had not long arrived. The quote above described his expectation of it. He had already appreciated that the diary would not

provide the whole story and his idea of the diary travelling with patients so that it could be continued is sensible.

In a different approach one of the diary team nurses suggested that Diane might wish to write something additional in her diary about being home and how she was feeling:

> *"If you read it, it says Diane its staff nurse* we didn't have a very good night with you… and they tell you why they didn't have a very good night with me and they say you were better in the morning. Telling you all the stages of the progress I was making. It is good to read and (the diary team nurse) said it would be good to write now after 12 weeks of coming home…Sometimes I do get a bit tearful, just thinking about the help and support and you can't express how you really feel…How much you appreciate things that have been done for you." (Diane 2 months)*

The value of the diary in coming to terms with their illness and the impact it has on their recovery in terms of limitations that are associated with their critical illness is important:

> *"... there were points which I was upset about obviously, but actually when I'd read it and I got to the end which for me is the day before I transferred down to* (specialist hospital). I actually felt a sense of loss almost because it told me nearly a fortnight of the time I was asleep, but I thought there is another 4 weeks that I don't know now and I think from all my concerns, hesitancy and all the rest of it, I think it's absolutely brilliant." (Clara 6 months)*

Clara describes in the quote above that it was emotive reading her diary and despite this it was information she needed to find out. This is evident in the words *"sense of loss"* when it told her about her 2 weeks in the one hospital, but stopped then because she was transferred for specialist care and there were 4 weeks her diary cannot help her with.

> *"It would have been nice to have been explained, oh today we have done test for legionnaires…, but it would be nice to know that, because I have been having it drip fed by my husband really." (Emily 2 months)*

There is a trend in Emily's first interview that she feels dissatisfied with her diary. It lacks the depth of detail that she feels she needs about what happened to her. Although her husband has told her about some things, the use of the words "drip fed" suggest that she does not feel fully informed and believes some information has been held back. This sense of missing information has left Emily still needing to know what happened. It wasn't until the twelve month interview that Emily actually read through her diary:

> *Researcher: "In terms of the diary have you looked at it since we last met?"*
>
> *Emily: "Yeah I have looked at it and it wasn't quite as bad as I thought. There were no pictures in there, thank goodness. They didn't have any apparently. There was just a few notes that the nurses would write in…it was quite helpful, but you are still out of it, aren't you. So no matter what they you read…it is a little bit surreal…but it was good cos at least you know what was going on…I look at it as part of my life I have got to get over…" (Emily 12 months)*

The fact that most participants described reading and re-reading their diaries during the twelve months the study data were collected suggests that the process of understanding how ill they were and making sense of what happened is a lengthy one.

> *"Well the diary makes my time better, gives me peace of mind...and it's something I can always refer to and read it again and again and again, which I find comforting. Nice" (Beth 6 months)*

Their diary was also a means of forming connections with the nurses and an aide memoire to events that they cannot remember:

> *"It was a way of letting me know, to me anyway, that they knew about me, that I wasn't a slab of meat; which is always the cliché of it isn't it? That I wasn't: that though they didn't know me; they had tried their best…I felt it was quite personal yes and that came across in it." (Clara 6 months)*

It is clear that participants' use of their diary varied. All, apart from Emily, read their diary at the first opportunity after they were given it. Some dipped in and out of it when they had queries particularly about dates. When friends and family visited, most used it as part of explaining what happened to them and this led to discussion with others and re-telling of their story that was helpful in resolving missing time and constructing their own perception of their life story. Fundamentally they valued their diary as a window on the care they received:

"*I will be interested to read the diary and my only recommendation is because I moved the diary should have gone with me. When you come out and recover it would be the complete story" (Graham 2 months)*

There was a sense from data that participants felt detached from the life threatening events that occurred because they struggled to relate to something that they did not feel part of, even though in reality it did happen to them.

"In a strange way it is a nice document to look back on and it's not because I am weird, but it is a part of your life and I think you need to look back on it sometimes and reflect and think well, there is a fine line between I suppose life and death sometimes…I think it has changed my outlook on life." (Graham 6 months)

Following his life threatening event Graham had a few setbacks requiring further hospital admissions during his recovery and he decided to retire from his job and concentrate on life with his family. He valued his diary and remained an advocate that there should be a continuation of the diary between hospitals if a patient is transferred.

Graham: "I still think it is a pity that it didn't go with me from the local hospital to the specialist hospital. It filled in a lot of pieces, because it's a jigsaw at the end of the day isn't it?

Researcher: "So you wanted the story from beginning to end?"

Graham: "The full picture" (Graham 12 months)

They try to use whatever sources of information are available to them to form a picture of events, to help them understand how ill they were and what was done to them and for them while they were so vulnerable, but did not always want to read parts of their diary, specifically written by family:

> *"They have both filled it in (diary) and they have both told me everything. It's sad what I have put them through, but then I didn't do it deliberately and I think that is partly why I don't want to read the diary at the moment, because everyone has contributed in to that and I don't know that I am strong enough yet to have the harsh realities in front of me" (Clara 2 months)*

The diary seems to counteract participants' sense that their lives have been disrupted through their "being out of it". Participants describe a need to know what happened and to try to understand these events and in most cases their diary helped.

> *"It's showing how busy they were even though I was sleeping my time away. How much was going on while I wasn't awake." (Clara 6 months)*

The diary can act as a representation of how ill participants were and in doing so can bring home the life threatening nature of events:

"It has made me appreciate life. It hasn't come without its ups and downs…I have come out stronger from it. I'm just very grateful to be here" (Clara 12 months)

Some publications about patient diaries have suggested that diary entries should steer clear of potentially sensitive issues, such as providing too much detail about the life threatening situation or uncharacteristic behaviour patients may have displayed (Jones, 2009a, Egerod & Christensen, 2009). However this potentially undermines the value of the diary for patients and adds a paternalistic stance to the concept of nurses and other HCPs writing on behalf of patients. Study data suggests participants did want honest accounts that followed the ups and downs of their critical illness journey; including the life threatening part and to know that any uncharacteristic behaviour was normal when waking from sedation.

Some participants felt that what they had experienced, in their capacity as the critically ill person, was hard for family and friends to contemplate and understand:

"...when you come that close to 'meeting your maker' certainly it's a very sobering thing for anybody and until it has happened to you I don't think anybody can realise what it is like." (Ian 2 months)

The fact that these critical care survivors have suffered a life threatening event (with no memory of it) seems to have triggered what is termed an existential crisis. This is

said to occur when the answers to questions pertaining to the meaning of life and our place within it, fail to provide comfort and peace of mind (Henoch & Danielson, 2009).

> *"I have got mixed feelings about it. I think what they are doing is fantastic, but I don't know if I am ready yet to read it. Because I still feel a bit sort of weak and weepy, but I think at first I was going to say no I didn't want to go and get it, but then I thought no, many people wrote in it and even if I don't feel ready to open it on my own or...what I do. I then thought I will go down, because although it would only cover the time I was in * (first hospital); that was perhaps, was that the more traumatic time?" (Clara 2 months)*

If these feelings, as described by Clara above, are not managed appropriately there is the potential to cause significant psychological harm. Furthermore, combining the confrontation of collecting the diary as well as offering a visit inside the critical care unit could be a step too far for patients, as demonstrated by the participant below:

> *"...when she asked me did I want to go and have a look around I was like oh no, don't want to know any of that... I wouldn't want to go back, either way! No, I think that is something that's best left, but somebody else might feel totally different." (Emily 6 months)*

Bearing this in mind, the way in which the diary is handed over and provision of support thereafter needs careful consideration. This is a matter of concern when use of diaries in critical care is expanding, potentially without appropriate resources in place to provide support:

"...she just gave it to me... I looked in a few of the things soon as I got it actually, that night I looked at one or two, skimmed through a few things that they had said, but I couldn't cope with their readings where they (family) had put in. What he had written and my daughter and son, couldn't cope with them." (Fran 2 months)

Some diary material was particularly emotive for participants to read, such as the openness of family entries about how they felt while their loved one was critically ill. Also bearing in mind they were reading their diaries often alone at home:

"...it got me upset, thinking and reading it so I thought that's it. I made sure I read it everything all the way through and I did read it. I couldn't keep going back to it, it upset me...I haven't looked at it now for quite a while. I leave it out on the top in my back room...sometimes perhaps I will flip through it and look at the dates and things…I think I found hardest, looking what they had and my husband what he had written as well." (Fran 6 months)

In the case of Harry the thought of collecting his diary was overwhelming for him, so he chose not to collect it:

"I didn't go down and get my records (diary) because I was too scared. I didn't want to know what I had done in intensive care because, but they did tell me a little bit. The stoma nurses were saying that I was ripping my pipes out, which I can't remember..." (Harry 6 months)

However collecting the diary was a means of regaining control and confidence for some participants:

> *"…when I came out of ICU, I did lose a lot of confidence. I don't remember anything, so I was reading my diary." (Diane 2 months)*

Diane read her diary and finding out about what went on while she was unconscious, that nurses treated her as a person even though she was unable to interact, was important to regaining her confidence during her recovery. Fundamentally needing to know what happened by reading their diary was a priority for those participants who wanted to collect their diary. In essence, participants were striving to piece together their critical illness story so that they could incorporate it coherently within their mind and remove the unease left by the rift in their life story.

> *"I will start to write again now, because it is a year up and I will write in there" (Diane 12 months)*

Diane is the only participant, advised by a diary team member during diary collection, to contribute reflective pieces of her own during her recovery. This is something that she obviously felt was useful to her and the anniversary of her illness was a trigger to make another addition.

The diary plays a key role in providing an opportunity for patients to confront what happened to them:

"I think that in a lot of senses it's partly making someone face up to really what they have been through." (Clara 12 months)

The diary can provide reassurance about the care participants received, which may help in re-personalising the critical care illness events from which they have felt detached:

"...I know by the diary I was well looked after in ICU...and everybody was kind and helpful. I couldn't have asked for better. I was definitely in the right place." (Beth 6 months)

The diary can provide reassurance especially in relation to the lost time participants had to cope with:

"...that's the important days, those 10 days when I was really ill and yes for me it's like a comfort blanket. It really is. So whoever thought of that deserves a medal. I think it's a wonderful idea I really do it gives me a lot of comfort and I can always go back and read it again. It's something you have always got now, so those 10 days don't play on my mind because I have got my diary and I can always refer to that and talk to my family about it. It's very comforting." (Beth 6 months)

Alternatively when the diary did serve the purpose of demonstrating how ill the participant has been and their progress, it prompted one to want to add to their diary once home:

"I think it was a really good, yeah I think it has done me good and it is good to know what intensive care have done for me...like I said to see how ill I was and what they was doing to me for me to make the progress and to gain the level that I should have been. I think it is a marvellous idea really. That's why I want to write in there now things that after a year..." (Diane 12 months)

Ewens *et al*. (2014b) identified in their study that after the patient took ownership of their diary some continued it by writing entries during their recovery and noted there is a lack of research about this aspect of diary use.

7.5 Benefit versus harm

7.5.1 Benefit

The diary is potentially a supportive resource for information, clarification and reassurance. The diary may act as a means of participants gaining understanding about what happened to them, but fundamentally they need to be prepared and ready to face this information:

"I have read bits of it. I haven't really sat down and gone through it all yet. I don't know whether it is the fact that you don't want to get upset either...I don't know if it's the fact you want to know, or am I scared to know, because if I break down will it bring on, I don't know if I would be able to stop to be honest with you. I think that's what it is as well, giving in to it, isn't it?...It has happened, forget about it, but there is something nagging me that yes I have to go down this road to, not forget about it, but to put it behind me..." (Emily 2 months)

Having a diary can help patients to gain coherence about the rift in their life that has occurred due to their critical illness, sedation and ventilation. By understanding what happened patients can potentially relate to the life threatening event that occurred, so that they can be realistic about their physical and psychological recovery.

The diary played a role in the recovery process for some participants by outlining their progress and providing a sense of ownership of the information that constituted their critical illness journey: a sense of knowing what happened and therefore regaining of control:

> *"I think I would have had to ask a lot more questions because I have not remembered things, but the diary does give you a lot of detail of what actually went on. I am glad that I did have that otherwise I would only have what my family had told me. I must have been a strong person to pull through that. The diary tells you how I was and how I was doing and how many days I was in ICU. Like each day the progress and the progress I didn't make and what they actually did for me…Just to read it, it is nice. The knowing is nice, knowing what happened." (Diane 2 months)*

In addition, the reassurance of being cared for and knowing what happened formed part of the recovery process by facilitating a coming to terms with and acceptance in participants about what had happened to them:

> *"They were just caring for me and looking after me and that was all. That's all you need because I couldn't remember anything. I just needed the care and*

attention that they gave me, but it is nice to know things were going on. Although I can't remember them, it's just nice to know...I have accepted it I think. I can't change it or do anything about it. I am one of those people who want to know what's gone on and that way I can accept that it happened and that's it. I am still here and that's the main thing." (Alice 6 months)

As a source of information, the diary therefore plays several roles: an aide memoire, where participants can check up on what happened on certain dates or during their critical illness journey. The diary can act as a way of providing participants with insight into the reality of their critical illness when it is outlined chronologically. The diary acts as a source of information that complements (validates) or goes beyond that of family and can provide reassurance about care provided to them as a person:

"...it was important to know where I was and what was happening. I think it's a good idea. It does help you. It has helped me enormously…Well I wouldn't have known what to ask would I? You can't expect my daughter and him (husband), they weren't there all the time whereas the nurses were…" (Beth 6 months)

The diary played a part in participants' acceptance of the reality of what happened to them and provided a renewed appreciation of life. Having some concept of what happened during time participants felt they had lost, was a crucial part of the recovery process for those participants who wanted their diary. As noted in the previous chapters people's life story narrative usually forms an uninterrupted continuum, it is evident from data in this study that a rift or disruption to that is a hugely unsettling concept. The diary has potential to allay some of the concerns

participants might hold about their critical illness journey and it can be a form of aide memoire about the *"lost days":*

> *"...instead of suppositions and not knowing it's given me peace of mind, which is a big thing. It's like a little comfort blanket and I will go back and read it a few more times and I think I don't remember that from last time, because I am one of these, that I'm a quick reader and then I tend to skip and then I think oh I don't remember that..." (Beth 6 months)*

The fact that Clara raises the potential need for counselling is very interesting and highlights how much of an impact her critical illness experience has actually had on her. The diary can act as a means of coming to terms with what has happened by providing insight into what happened daily and reassurance about care. However, additional support, such as counselling may be required. The diary team members are not qualified counsellors; this means that linking with a clinical psychologist may be beneficial.

> *"I was the one that was asleep through it all, but yes I think the diary is great and offering someone a little bit of counselling about what has gone on, what has happened to them, helping them to come to terms with some of it, because to have 6 weeks of your life missing...So for the times you could actually give someone information would be good...once they started putting me to sleep and all that at least someone was taking that over and giving me back some of that time. I think that's what it was for me was helping me just understand some of it." (Clara 6 months)*

The diary entries therefore are fundamental for piecing together what happened for participants and family, but also as a resource to share with friends. Participants want the diary to help them express the missing time of their critical illness to themselves and to others. Participants suggested that their diary should validate what they have been told by family and to enable them and others to make sense of how ill they were. The more their diary contains, in terms of main threads that combine to form their story, the better.

> *"I thought I didn't want to really start opening a can of worms. I thought oh I am coping alright with it and thinking oh don't scratch the surface too much because...I don't want to go there...I suppose he talked me into getting the diary really if I am honest." (Emily 6 months)*

Collecting the diary does require the participant to be ready to do so. In Emily's case, throughout this chapter, it is clear that apart from Harry, who chose not to collect his diary, she was most negatively affected by her critical illness event. She described being persuaded by her husband to collect her diary. She is a representation of the potential conflicts, psychologically, that patients may go through if they do not want to face what happened and prefer avoidance.

Data demonstrated that use of a critical care diary can shed light on what happened during participants critical care stay; helping them to comprehend how ill they actually were and how the experience has affected family as well:

"I actually read it here on my own…there were points where I got quite upset about things, because it made me realise perhaps what I had been through and what other people had been through with me...Overall I felt it was filling in gaps, telling me what it says, the story of the time that I was with intensive care and how the journey travelled through...in that format it can make sense and… actually realise what you have been through…Better for me has been the diary, because it's filled in part of the black hole, that hard as (my family) and anybody tries to fill it for me they can't, as having that physical book from it. Hard has been getting your confidence back with your own body, because your body let you down so badly and trying to come to terms with what's happened and what journey you have been on." (Clara 12 months)

The diary did not always tell enough about what had happened, the diary team nurses need to be aware and emphasise the importance that the diary reflects the severity of illness with its ups and downs. When the diary did cover the main concerns, it was able to be used for reference for the participant and friends, especially those who were unable to visit:

"I think it's a really good thing for me to refer back too and for my friends as well… So it's for them as well as me. They can read it...it's a great help I think, rather than me tell them, well I can't tell them because I can't remember a lot of it. You know I can give it to them and say well that's what happened to me." (Alice 12 months)

The benefits associated with provision of a critical care diary are reliant on inclusion of diary use as part of an integrated support system. The current study demonstrates that diary use in isolation without follow-up, or alternative means of support, are

cause for concern and undermines the principles and purpose of providing a diary for patients

7.5.2 Harm

Starting with the diary process aligned to invitation, collection and handover of the diary to the patient. There needs to be careful consideration given to how best to establish these processes to meet patients' needs. Participant data explored earlier in the chapter identified that patients have just recently arrived home from hospital following their critical illness admission when their invitation to collect their diary arrives at six weeks. There was no accompanying supportive information providing any explanation about what to expect of the visit to collect the diary or the purpose behind it. Uncertainty and loss of control over their lives has been identified as problematic for participants in the current study and this process does nothing to allay those feelings. Furthermore participants were asked to come to the critical care environment for the appointment. Bearing in mind they cannot recall being there and they are still trying to comprehend what has happened to them. It is a confrontational and emotive expectation very soon into their recovery. Especially when they are offered opportunity to look around the unit as opposed to discussing their diary and the diary is handed over like an afterthought as the participant leaves. This initial phase of introducing the patient to the diary is potentially overwhelming and could be off putting.

Exposing a patient to a diary that they may not be prepared or ready to read could be harmful and increase psychological problems rather than reduce them. In order for the diary to be of use to the participant, they firstly need to be ready to want to read it, as with Beth. But, it was a shock to her when she realised that she had almost died.

> *"They said don't read it all in one go. Well what did I do? I read it all in one go didn't I!" (Beth 12 months)*

The handover process at the study site has adapted now as a means to introduce patients to their diary and talk through the key points to avoid them reading certain content on their own. This does not mean staff should avoid putting in content about the patients' illness journey that may be difficult to read, as that negates the potential value of the open and honest dialogue participants said they wanted.

Diary teams need to be mindful that as an intervention it may only work for some and not all patients. Therefore diary use in isolation from other supportive processes seems to be potentially dangerous to patients' health and wellbeing. If a diary is to be used and harmful effects are to be avoided or risk minimised then follow-up or alternative supportive strategies need to be in place, such as patient and relative support groups and access to a clinical psychologist if there is any concern.

Some family members could not face the diary and this demonstrates how confrontational reading the diary is, not just for the patient, but for family who

witnessed the events that their loved one cannot recall. While talking about the critical illness and diary content may help some, revisiting traumatic events may be a step too far for some patients and their family. There are different coping mechanisms at play in individuals' ways of dealing with traumatic life events. In some cases, people just want to forget the trauma and this may work for some, but for others they never really get over it and psychologically this can manifest itself with mental health problems such as anxiety and depression. In this situation the impact can be on both the patient and their family members.

Benefit versus harm of diaries remains to be explained in the research (Ullman *et al.,* 2014). The current study adds insight into participants' experiences, identifying that while the diary is potential useful in terms of facilitating coherence about events for patients, there is also the potential for a diary to maintain or add to existing incoherence and lack of clarity and control for patients. The concern then becomes the risk of adding to or triggering psychological problems where there were none; which in turn negatively impacts on the process of physical recovery. Supporting this Tahir (2014) argues that expecting certain patients to confront what has happened to them, could actually be detrimental and incur psychological harm where there was none.

The critical care experience is stressful for patients and their families and the psychological and physical debility that can linger afterwards for critical care survivors can be challenging to manage (Desai *et al.,* 2011). Anxiety and depression, even PTSD, has been linked to critical care survivors enduring complications

(Needham *et al.,* 2012). Critical care diaries have been implemented with the intention of helping critical care survivors, and their families, in the aftermath of the life threatening events that have occurred (Jones *et al.,* 2010, Jones *et al.,* 2012, Ullman *et al*., 2015).

Implementation of a diary, in isolation from on-going support in the initial period of recovery, is something participants in the current study felt needed addressing. Furthermore, this thesis has already outlined the known detrimental implications of one off debriefing; advocating a series of opportunities for debriefing to occur seems to be the way forward. Reading and re-reading the diary is described by Jones *et al.* (2010) as a self-help debriefing tool; but this seems to be simplistic and potentially detrimental in terms of critical care survivors' well-being. Even a year after discharge from critical care, participants in the current study remained in need of follow-up support. Furthermore, some participants suggested that follow-up in conjunction with diary use could help in the recovery process by facilitating closure:

> *"A bit of a follow-up...I think in a sense if they sort of with the diary and meeting up with somebody to talk about things it would give a sense of closure. Closure from certain issues and give people a way forward from it because it's not something that people go through that often." (Clara 6 months)*

Effective communication alongside appropriate aftercare support could play a significant role in patients' psychological well-being (Rattray, 2013).

"I see my family most days, when I first came home my sister, she works for home care, she used to come in and see me in and out of the bath when I was still unsteady on my feet. At the time when I first came home if I needed anything I had close family around me. I haven't had anybody else come and see me since I came home mind, all I have had is you, nobody else has been to see how I am progressing or anything!" (Diane 12 months)

Diane's quote above emphasises the abandonment she felt from the healthcare perspective of follow-up. She had visited her GP, but her need for a visit or appointment to see someone related to the critical care events was about acknowledgement of the life threatening nature of what she had been through by asking to see how she was progressing.

7.6 Diary role

The participants' concerns are *"being out of it", "lost days"* and *"memory loss"* about their critical care admission. Furthermore, they faced both psychological and physical limitations during their recovery, with a need to know what happened so that they could understand how ill they had really been. Thus it was important that they were given their recovery in context and to accept and forgive their body for letting them down. The need to know what happened and to piece together their critical illness story involved accounting for their missing time, being able to relate to this significant event that happened to them, but that they felt disconnected from through memory loss. It is important for participants to form a chronological timeline of their missing time as an individual's life story is usually complete. The rift in their life story

created unease, loss of control, uncertainty and negatively impacted on their sense of identity.

The diary can act as a vehicle through which participants are able to make a connection with their missing time and the nurses who cared for them. Ultimately the diary provided reassurance and was a source of comfort when it provided enough detail, in chronological order, for the missing time. The way nurses wrote in it in a personal and caring manner left participants feeling reassured, that despite their unconscious state someone was protecting their wellbeing. When the diary was too brief or did not represent content to account for each day, participants were left with questions not answers and increased uncertainty and it was therefore potentially counter-productive.

Participants referred to their diary as a reminder of what they had been through when they had a bad day during their recovery. It acted as a resource that they could show to family and friends and it could explain what happened to them. However, in Emily's case, her diary did not cover both her admissions to critical care and she described her disappointment that she could not use it to speak on her behalf when she was with friends. Participants, on the whole, were proud of their diary because it represented their survival, often against the odds.

The literature available about critical care diary use suggests that the diary is usually read to the patient by the nurse at the handover, which occurs at a follow-up

appointment (Egerod *et al.,* 2013, Nydahl *et al.,* 2014). The purpose of a face to face diary handover is to facilitate an open discussion, guide through the diary content and enable questions to be answered; avoiding reading the diary alone (Jones, 2009a). In the study setting, the diary handover was not a run through of the diary or a discussion based meeting. Instead the diary was handed over after the invitation to look around critical care; like an after-thought. The diary process only provided one off contact to hand it over. There was no subsequent follow-up opportunity to address any concerns.

In the current study participants perceptions and experiences of their critical illness were explored in a longitudinal approach with interviews at two, six and twelve months. This provided valuable insight over a significant period of their illness trajectory and has not been provided previously in the context of critical care diary studies.

The following quotes represent individual participant's perceptions of their diary, its role and impact on recovery during their interviews over the year of the current study. The aim of this section is to present each participant's perceptions over time to facilitate insight into the similarities and differences of views.

Alice

"Hope to fill in a couple of spaces I suppose." (Alice 2 months)

"Those two days that are missing. That was the one day that my grandson actually came in with my daughter. It doesn't say about him being there, as I say it's one of the days that was missing." (Alice 6 months)

"They were all telling me what I was like and I wanted to see what I was like myself you know and I think because they told me they had a photograph and then I didn't have one…" (Alice 12 months)

"It's a great help I think, rather than me tell them, well I can't tell them because I can't remember a lot of it. You know I can give it to them and say well that's what happened to me." (Alice 12 months)

Alice wanted more information and not having a photograph was a regret for her in terms of confirmation of how ill she had been. Alice made contact on the second anniversary and was updated on the study. She shared that the anniversary prompted her to look at her diary again. Over the year Alice felt that not having her photograph as promised meant she found it hard to conceptualise how ill she had been. Her diary did not fully validate her illness, because of the missing photograph, and failed to provide the coherence that she sought, because of the missing dates that left her with uncertainty. However she did feel her diary contained enough of her critical illness story to be able to share it with others as testament of what she had been through.

Beth

> *"I can't remember either (to husband). Well I got the diary here so we can always check on that…Well you feel more in control, not so out of it. It's hard to explain. It's comforting. I found the diary comforting." (Beth 2 months)*

> *"The person that writes in it is the person that's the person that's looked after you for the 12 hours. It tells you enough to give you comfort and I find that very comforting." (Beth 6 months)*

> ***"****I can prove I have been there. I have got proof, they don't have to take my word for it; they can read it. I still enjoy reading it. I don't know whether you could say you get a bit of comfort from it, that's the way to look at it. To me it's a comfort to think I was so well cared for." (Beth 12 months)*

> **…***everything then to do with my health it goes in. I put it in there, anything important. I just put the papers in the diary so I always know where everything is." (Beth 12 months)*

Over the year Beth found her diary useful as a source of regaining control, comfort, reassurance and peace of mind about her care. It was evident some discussion and clarification of information may have been beneficial as part of follow up support. Beth used her diary to keep information about her health and appointments safe. She read and reread her diary as she said she was not able to take it all in. This helped her at six months and twelve months to form a coherent overview of what happened on her lost days. The content was meaningful to her and helped her to find resolution for the rift in her life story.

Clara

"I have got mixed feelings about it. I think what they are doing is fantastic, but I don't know if I am ready yet to read it. Because I still feel a bit sort of weak and weepy, but I think at first I was going to say no I didn't want to go and get it, but then I thought no, many people wrote in it and even if I don't feel ready to open it on my own or however , what I do. I then thought I will go down, because although it would only cover the time I was in (first hospital)" (Clara 2 months)

"*I didn't have a look (at the diary) immediately, my husband was on afternoons and I just sort of thought right I have got to have a look and yes there were points which I was upset about obviously, but actually when I'd read it and I got to the end which for me is the day before I transferred down to* (specialist hospital). I actually felt a sense of loss almost because it told me nearly a fortnight of the time I was asleep, but I thought there is another 4 weeks that I don't know now and I think from all my concerns, hesitancy and all the rest of it. I think it's absolutely brilliant." (Clara 6 months)*

"I think then that when you first see all your scarring, you can think oh my God what the hell were they doing, whereas the picture explains it. Ah, those were the tubes… the little feather scars I've got is where the trache was put in place and all things like this, you know and I think it helps. It just helps with the explanation..." (Clara 12 months)

"I want to take just some sweets or something down at Christmas and take it down for each of them…I am not the only story that passes through their hands and I think it comes a point where you have to move on, but it's almost a way of saying I still appreciate what you did for me…" (Clara 12 months)

Clara demonstrated determination and motivation to recover and despite being hesitant to collect her diary she found it strengthened her resolve. She found her photograph useful in helping her understand how ill she had been. It also reassured her that her dignity and respect were maintained. Over the year Clara's perceptions of her diary changed from one of hesitancy and concern, where she did not feel ready to know what happened. At six months she had read it, seen her photograph and had started to feel it was making sense to her. By twelve months Clara felt the diary gave her reassurance, represented a relationship between her and the nurses, confirmed for her how ill she was and was clearly meaningful to her. She compared having the diary to the time she has no diary during her transfer and it is a significant difference for her sense of coherence over the rift in her life story and self-identity.

Diane

> *"If you read it says * its staff nurse* we didn't have a very good night with you and I can't remember and they tell you why they didn't have a very good night with me and they say you were better in the morning. Telling you all the stages of the progress I was making. It is good to read…" (Diane 2 months)*

> *Researcher: "If you didn't have the diary would it matter?"*
>
> *Diane: "Yes because I would have liked to have known, from how ill I was to the progress that I was making and the progress that I did make. I think that it was a great help and I would say to anybody that was in intensive care to go back for their diary." (Diane 6 months)*

"I will start to write again now, because it is a year up and I will write in there." (Diane 12 months)

Researcher: "So what do you think you will do with your diary?"

Diane: "I will just write, because I wrote in the first few months. I will just finish it off now and I will just write in the way that I am feeling and you know, obviously like my progress and want to carry on the way that I am going, you know. Just really things in general, how I am feeling and different things. I think I have made excellent progress. I mean I will say it's been nice talking to you throughout the year, it's been nice." (Diane 12 months)

Diane had a photograph which helped to confirm the severity of her illness, being visual it had instant impact. She had opportunity to view her photograph with staff, unlike the others. This meant she was able to ask questions and link that to her visit into the unit for explanation as well. Some participants could not face going into the unit as it was too confrontational too soon and they were not ready. She continued her diary by adding reflections on her progress and photographs as she improved. Over the year Diane used her diary during her recovery as a means of charting her progress, with reflections and adding photographs as she achieved goals such as trips out, parties as examples. Like others she found her diary reassuring, personal and also a source of family support through their motivational and encouraging entries to the diary. Through her diary Diane found a renewed appreciation for her life and self-identity within her supportive family. She did want someone to acknowledge how ill she had been from a hospital contact perspective.

Emily

"*I haven't really read it and taken in that much so maybe when I do read it through. I suppose that's another thing. Cos I wasn't really going to go and pick it up and part of me didn't want to go down that road. So I have only read little bits of it. Maybe when I read it fully then I might think oh, no nothing needs to be changed. But I think it has to be for the patient then. For me, you need to have something in there to explain to you how ill you were I think, for me anyway."(Emily 2 months)*

"There's not an awful lot in there really, well there is but, not the second time I was in there is nothing in there then and my husband hasn't got around to finishing it off yet, because he wanted to have, when I was in he had people to write things, like friends and family to put in the diary, but he hasn't got around to finishing that part of it yet…" (Emily 6 months)

"…It was quite weird reading, like the nurses would put hi Emily and talk to you like as if they knew you, but you don't know them and like you will probably never see these people ever again…but it was lovely. They were just saying what was going on through the day and what the girls were doing and that's a bit phwoof you know… but I look at it as part of my life that I have got to get over and no doubt after I get this next couple of weeks over with I'm sure it'll be fine. I think it is really difficult that you was in intensive care and you don't know nothing about it. It's like really weird, but of course you are not told it either are you?...that there is nothing after really…It would be nice for people to be able to feel secure really…you just feel sometimes as if you are lost. Cos the only connection I had with the hospital after was seeing the Consultant and I think that was a good thing, does that make sense? Cos everybody wants to be reassured don't they?" (Emily 12 months)

Emily did not use her diary initially because her husband had planned to add cards and messages he collected while she was ill. She was also persuaded to collect her diary and admitted she would not have wanted to know what happened if it were her decision. However over time she did feel able to read it. It was only superficial and didn't capture her second admission, which for her was still a continuation of her critical illness. She did not want a photograph, but her husband drew a picture with all the tubes for her to have some insight. Unlike other participants, Emily's diary was too superficial and thus failed to provide her with reassurance. She did feel it was written in a personal way, but she did not get that sense of relationship, care and dignity others had felt on reading their diary. Her coherence of her rift in life story remained confused with her finding the content was not meaningful or comprehensive to her needs. A hurdle for her was her diary failed to confirm her life threatening illness and she needed that comprehensibility. Her expressions about her self-identity in her interviews demonstrated a sense of detachment initially, but that did improve with visits to her GP and possibly by being able to talk it through in interviews.

Fran

> *"I wanted it to say what dates I went where and when and I wanted it to say what was done to me what day and when and things like that. Yes I did find that helpful." (Fran 2 months)*

> *"It's personalised what they have said. Even my physiotherapist put one in, bit in there the one day." (Fran 6 months)*

Researcher: "Have you looked at your diary at all since we last met?"

Fran: "No, I haven't picked it up…I haven't looked at any of it or anything. It crosses my mind now and again about it and different things go through my mind about it, but nothing to worry about you know, or go and look at it. No, it's sort of past I suppose. It's gone and that's it." (Fran 12 months)

Initially Fran could not read what her family had put in her diary as it was too emotive. She didn't engage with her diary as much as others during the year, but she said she liked the reassurance it was in a safe place should she want to read it again. Fran's approach seemed to be that it was best not to dwell on what happened. It was nice to have a diary and it did help her feel reassured about care and a sense of coherence about what had happened. It was not a resource she intended to keep revisiting as a reminder.

Graham

*"I think in one way it will help to sort of you know they are pieces of the jigsaw over that period of time. There are going to be some missing, you know because I was in the * (specialist hospital) longer, so there are going to be pieces missing...Yes even just for your personal satisfaction that this happened on that day, that happened on that day" (Graham 2 months)*

"I realised what went on then I suppose and what really happened I suppose for that short period of time. That's why I think it is important that the diary should go with you so you get a full picture…At least it gives you a balanced view of what was happening. If it had just been the family writing in there then I wouldn't really have known what was going on…" (Graham 6 months)

"I have retired from work. Man of leisure, well I say man of leisure, but I don't know. We seem to be here, there and everywhere…had my pacemaker checked in May. I haven't got to go til next May now. Yes so hopefully it is all ok. All behind us with a bit of luck…" (Graham 6 months)

"...so as I say that would be my only recommendation that the diary went with you if you did have to move and perhaps, not in my case I couldn't do it, but perhaps if you are conscious you could write in it yourself or get someone to write in it for you what you wanted to say; how you felt on a particular day, perhaps how upset you might have been. It could work for two purposes then. One it's a story of when you were in there and two it could be to improve practice. I see it that way." (Graham 12 months)

Graham saw his diary as an opportunity to piece together what happened. He, like Clara, wanted a continuation of the diary between hospitals as he found it helpful in his recovery and was left with only part of the journey captured for him. Over the year Graham was keen to explore his diary and share ways in which it could be improved. He found it useful to help with the rift in his life story, self-identity and coherence about what happened to him.

Ian

Researcher: "Did they have a photograph in the diary for you?"

Ian: No in fact that photograph was taken by the dietician early on and then I had to do another one just before I left, showing the difference. I said I had no objection to them using the photograph or whatever.

Researcher: "Would you have wanted one if they did?"

Ian: Yes I would have had a photograph of me with all my tubes in. I would have been quite happy with that. Yes it wouldn't have worried me." (Ian 2 months)

Ian: "I love the personal way they have written all that, you know it's very comforting, you know. I wasn't driving at all then so I read it on the way home, couldn't wait to read it."

Researcher: "How did you feel reading that initial page where it says how poorly you were in theatre and when you came back?"

Ian: "Well it made no difference to me, in fairness to the surgeon; he told me there was a good chance you are going to 'pop your clogs'. Really, so anything after that was a bonus…when you come that close to 'meeting your maker' certainly it's a very sobering thing for anybody and until it has happened to you I don't think anybody can realise what it is like." (Ian 6 months)

Researcher: "In terms of the diary have you looked at it since?"

Ian: "Oh yes, in fact I find it quite fascinating, to me it's quite enjoyable reading because it's written in such a one to one personal way…take care… you had a good night, I have been looking after you all night…So you get this cocoon effect and that's what I had when I was in hospital, I was cocooned… It (diary) is nothing short of a chronological reminder of what was probably worse for other people than for me. It must have been devastating…to be on the other side of it." (Ian 12 months)

Ian was grateful that be alive after his critical illness. He found the personal nature of the diary entries reassuring and like Clara was determined to recover and enjoy life. Over the year Ian shared that he enjoyed reading his diary and it acted as a conduit

to share with others what he had been through. Thus for him his diary provided validation of how ill he had been. He felt reassured and like others that there was a caring relationship evident in nurses diary entries. Ian's diary seemed to be coherent and to acknowledge how ill he had been so he found it meaningful.

These aspects discussed below have been identified as key components of the diary role and purpose in the current study:

A diary can play a role in providing reassurance and acting as a bridge between HCPs and patient relationship that did not occur while the patient was unconscious. Through diary entries HCPs can share that they cared for the patient as a human being. The diary has potential to provide a chronological account of the missing time patients' face. HCPs can write something on a daily basis demonstrating patient progress or not in an open and honest manner. There may be need for a retrospective element or addition of a discharge summary that captures all the key events and discussions that were held to ensure that the diary is coherent when read.

The diary can act to confirm or validate the severity of the critical illness in a manner that enables the patient to understand the reality of how ill they were as part of accepting it happened, coming to terms with it and being able to move on. Diary content can be meaningful to patients who read them and the intention should be that the diary can help the patient pull the threads of information together from the

diary, family and other sources to form their own interpretation of what happened to them that make sense to them. This new sense of coherence over events that occurred can repair the rift in their life story caused by their critical illness. Furthermore all of these aspects contribute to a regaining of control and self-identity after critical illness.

These aspects are considered further in chapter 8 p.247

Careful consideration about offering a diary and ensuring supportive mechanisms are in place for patients thereafter seems to be a crucial aspect of critical care diary use. Diary use is one potential means to help patients in the aftermath of critical illness. Some potential alternatives or support that could be used in tandem with diaries are outlined below.

7.7 Alternatives to a diary

Any form of rehabilitation after critical illness will have a cost implication in terms of both finances to fund it and in provision of staff to deliver it. However the potential benefits of follow up service provision relate to improved patient outcome through physical and psychological assessment and appropriate referral processes that can facilitate patient recovery in a realistic manner. While Cuthbertson *et al.* (2009) provide insight into the cost implications of follow up they do not capture the value to the patient in terms of psychological and emotional support. Longer term impact has been recognised such as sleep disorders, concerns about quality of life and inability

to return to work (Audit Commission, 1999). However, discharge from critical care following critical illness can result in emotional concerns from joy at surviving and leaving critical care to fear and anxiety related to feelings of abandonment (Pattinson, 2010). Furthermore NICE (2009) describe the risk of nightmares, PTSD and acute stress disorders (ASD) anxiety and depression, mood swings and subsequent strain on family relationships.

Litz (2008) has highlighted in his work on early intervention and debrifing for trauma that initial stress and anxiety following a traumatic event is probably to be expected and is therefore 'normal'. Litz (2008) notes that any psychological or emotional intervention will need to be flexible as it may work for some and not others and it is important that such measures allow for variations in human reactions, response and needs. Litz (2008) also suggests that any psychological intervention, such as follow up, should be provided for those patients who clearly have signs of problems; as such services tend to be limited. Compounding this is the fact that longitudinal data pertaining to follow-up services does not exist. Subsequently it is currently unclear if support is required and if so what form it should take.

The literature suggests that critical care survivors may experience adverse physical and psychological symptoms that impact on their health related quality of life (Adamson *et al.,* 2004, Ulvik *et al*., 2008, Myhren *et al*., 2010, Rattray *et al*., 2010). According to Griffiths *et al*. (2008) there is a lack of rigorous longitudinal studies related to the long term follow-up of critical care survivors and studies have varied in their method and case mix; consequently realistic prevalence of such symptoms are

unclear. Further research into critical illness, survival and PTSD symptoms during recovery currently forms a topical area of discussion.

7.7.1 Follow-up

Follow-up of critical care patients has been questioned in a large scale multi-centre (three UK hospitals) randomised control trial by Cuthbertson *et al*. (2009). They compared one group receiving nurse led follow-up versus standard care of patients following discharge from critical care, which is no provision of any support. Results were measured using a health related quality of life SF-36 questionnaire at 6 and 12 months post discharge and incidence and psychological morbidities at the same timeframes. The questionnaire has been used in a multitude of studies and has proven to be a reliable and valid tool for assessment. The study concluded that nurse led follow-up of critical care patients had no impact on their quality of life or recovery (Pattison, 2009). However, NICE guidance (2009) advocates that we do need to find means of providing support to critical care survivors. Some qualitative studies have identified value in provision of follow-up services (Pattinson *et al.,* 2007, Prinjha *et al.,* 2009). Criticism of Cuthbertson *et al.* (2009) notes that the intervention provided in the study was ‘standardised’, ‘unidisciplinary’ and was delivered as a ‘too little, too late’ intervention, which has contributed to the conclusion that follow-up is ineffective and not cost effective (O’Connor, 2009).

The rationale for rehabilitation following critical illness (NICE, 2009) is to provide goal directed care using the multidisciplinary team to ensure individual patient needs are

addressed and O'Connor (2009) highlights the point that patients discharged from critical care in Leeds who received support as noted above demonstrated improved independence and reduced costs for NHS and social services. Interestingly Unroe *et al.* (2010) in their cohort study following a one year trajectory of 126 mechanically ventilated patients found that 56% of the patients were still alive, but of these 84% were unable to function independently and 44% showed significant reduction in cognitive abilities leading to a poor quality of life.

7.7.2 Debriefing

NICE (2009) guidelines for critical care rehabilitation support the results of a Cochrane Library Review by Rose *et al.* (2007), which is based on the results of 11 randomised control trials and does not recommend one-off debriefing sessions following a traumatic event. 3 of the 11 studies associated debriefing as a positive experience for patients whereas 6 studies identified no benefit and the remaining 2 studies identified debriefing as having a negative outcome for patients.

Research indicates that debriefing needs time and should not be rushed; time limiting a session can exacerbate problems (Litz, 2008). Arendt & Elklit (2001) identified 5 studies with debriefing lasting over an hour and having a positive effect as oppose to 6 studies with a negative effect associated with sessions lasting less than an hour. Timing of the debriefing needs consideration as debriefing too soon after a traumatic event is seen as detrimental as it is associated with negative patient outcome.

Interestingly Mayou *et al.* (2000) conducted an RCT in survivors of traumatic road traffic accidents and found that the control group fared better than intervention group who had received debriefing as their intervention. However, the intervention in the form of debriefing was conducted in the first 24 hours post event. It is recommended that debriefing is avoided in the first 24 hours post traumatic event resulting in injury due to associated negative impact on patients. In the Mayou *et al.* (2000) study participants probably needed more time to pass before debriefing was initiated and also the debriefer needs to be trained and experienced, whereas the research assistant had to take over in the Mayou *et al.* (2000) study.

Everly & Mitchell (1999) advocate debriefing between 24 hours and 10 days after the crisis, but never in the first 24 hours. It is believed that forcing someone to relive a distressing event in the initial period after it has occurred can actually embed vivid memories and negatively impact upon their recovery. According to Everly & Mitchell (1999) if the event is deemed catastrophic then debriefing should take place after 3-4 weeks has passed.

7.7.3 Clinical psychologist

The role of a specialist critical care clinical psychologist has been evolving in recent years. University Hospital Wales in Cardiff has employed one for over a decade in the capacity of support for HCPs, patients and their families and bereavement.

Peris *et al.* (2011) in Italy conducted a study aiming to verify that intra-intensive care clinical psychology intervention can decrease the prevalence of anxiety, depression and PTSD symptoms in trauma patients a year after discharge from hospital, home. The clinical psychologist role was to prevent and treat the psychological impact of trauma and critical illness in patients, care givers and healthcare staff. They employed three clinical psychologists covering via a 24 hour on call service. They provided bedside educational interventions, counselling and stress management approaches and coping strategies, which are all documented in the medical records. Once awake, patients receive on average 5-6 interventions. During the study relatives were provided their clinical psychology support separate from the patient.

Hatch *et al.* (2011) said that PTSD diagnosis during recovery from critical illness has variable estimates from 5-64% of patients according to studies that vary in design, case mix, method and timing of PTSD assessment. Therefore, they say, the extent that events prior to critical care admission or the critical illness or treatment itself contribute to PTSD following critical illness remains a mystery. While they recognise trauma as having a significant association with PTSD post critical illness, they also acknowledge that there is growing evidence of an interconnected relationship between admission to critical care and development of PTSD. They also consider the use of appropriately validated assessment tools and the need to involve psychological and psychiatric colleagues to ensure tools used are valid, reliable and psychometrically robust.

7.7.4 Support groups

ICU Steps is a patient and relative support group which began in 2005 and was set up by a nurse and patient; Mo Peskett & Peter Gibb. Together they use their experience to help others to set up and run their own regional support groups (Peskett & Gibb, 2009). A consideration in this process needs to be whether patient and family needs differ and therefore whether they can be met in a combined arena such as this support group.

There are now things like group support for relatives while in critical care. There are a growing number of websites offering support via information, stories in video format and a means for critical care survivors to feel supported in their experiences shared by others and therefore confirming they are not abnormal. Saying that should there be psychological concerns there are links to support.

7.7.5 Critical care discharge summary

Instead of a diary a comprehensive discharge summary can be used to capture the key events that have occurred in the patient's critical illness journey. This can then be sent to the GP as well as given to the patient. It is potentially less confrontational than a diary, but not necessarily aimed at being personal it the way it it written. It can be retrospectively written ensuring it is accurate in reflecting the critical illness journey (Bench *et al.,* 2012).

It is evident that HCPs need to be more aware of what patients actually go through. Added to this the patients illness history needs to be considered by HCPs on wards and if readmitted as there seems to be a focus on the here and now not on the whole picture of what someone has been dealing with and the physical and psychological implications for them as a result. It may be useful to encourage patients to write about their progress in their diary as part of a therapeutic process that can help reduce anxiety.

7.7.6 Therapeutic writing

Narrative is an important resource for patient who have been ill and it does not have to be narrative provided by others. Writing and reflecting on things that have happened can be cathartic and can be helpful for patients in coming to terms with what they have been through and how they feel (Pennebaker & Seagal, 1999, Dowling, 2011). Expressing these things can enable them to be processed in a coherent manner and can reduce psychological burdens (Bryant et al., 2011).

In the study Diane added reflections about her progress at six and twelve months and added photographs demonstrating her recovery. She found this a useful way of aiding her recovery process as it helped her reflect upon her milestones and the positive aspects of her recovery.

The majority of nurses are not qualified counsellors and some of the issues critical care survivor's encounter, potentially require a professional counsellor or clinical psychologist to intervene.

The diary, once read, could trigger psychological problems where there were none. The diary as a potential prompt for more questions could trigger anxiety or even depression if the patient is left to struggle alone. Diary use in isolation from other support mechanisms and follow-up is possibly a source of harm rather than a resource to facilitate recovery.

HCPs need to be aware of this prior to implementing diaries so that they can carefully consider the process and alternatives available. The findings suggest that a diary can be useful for some, but that participants wanted to be able to talk about their experiences. It is possible that by participating in the study and seeing the researcher for the three interviews, that the researcher herself, actually became part of the intervention that helped the participants. In essence, during the interviews the researcher was acknowledging participants had been critically ill and was a willing vessel through which they could tell their story, share concerns and feel they had been heard.

7.8 Summary of chapter

In Chapter 7: critical care diary: *"it's a piece of jigsaw"* participants described a process of reparation where they described needing to know what happened and how they hoped reading the diary could help them to repair the rift critical illness created in their lives, through capturing what happened to them and helping them to construct their illness story. Potential benefits and harm associated with diary use was explored. Repairing the disruption in their life, through coherence, was pivotal and integral to participants' self-identity.

The issue of being ready to know what happened: readiness, reparation and needing coherence are explored in chapter 8 as part of the emerging theory

The emergent theory aims to make sense of what participants have shared about needing to know and the importance of coherence about their lives during recovery. Perceptions' of their diary and the role their diary has played for them during their recovery has been explored and will be integrated within the emergent substantive theory in the next chapter.

Chapter 8: An explanation of the emergent grounded theory

A grounded theory of needing coherence: repairing the rift in life story and self-identity after critical illness and establishing the role of a critical care diary

8.0 Overview of chapter

The aim of this chapter is to explain how the conceptual categories and theoretical sampling and theoretical sensitivity led to the core category and emergence of the grounded theory from the data to form a substantive theory. The emergent grounded theory is presented using a conceptual map (see Figure 11, p.251). Using the conceptual map the relationship of the emergent theory to existing substantive theory, conceptual models, empirical and scholarly literature is explained. The delimiting process and reduction has been used to present the most salient points forming the substantive theory using figure 12 p.304. The substantive theory can be applied to clinical practice using figure 12 p.304 to outline the key considerations for HCPs involved in implementation and use of diaries in clinical practice.

8.1 Theory in the context of GGT

The constant comparative method is an inductive method of theory development. It requires the researcher to make theoretical sense of the diverse data through developing ideas using conceptual abstraction that renders the ideas at a higher level than the qualitative data being analysed. Underlying uniformities, differences

and similarities lead to more abstract concepts to account for differences in the data and eventually a substantive theory emerges (Glaser, 2008). Constant comparative analysis incorporates four stages (Glaser, 2008, p.4):

1. Comparing incidents applicable to each category
2. Integrating categories with their properties
3. Delimiting the theory
4. Writing the theory

Generating theory is an evolving process each stage provides continuous development to its successive stage until analysis is completed (Glaser, 2008). Writing theory encompasses the coded data, a series of memos and a theory. The memos provide the explanations for the categories, which become the major themes of the theory (Glaser, 2013b).

Theory organisation is about demonstrating variability on an abstract level. Glaser says variability can be challenging for the researcher as they try to find the best fit, work and relevance of the codes to generate theory. This can leave the novice researcher feeling confused, anxious and even depressed over their 'best fit model of integration' (Glaser, 2013a, p.3). According to Glaser (2008) the researcher needs to deconstruct the story within the data to enable generation of theory. The analytic framework needs to form a systematic substantive theory that provides a 'reasonably accurate statement of the matters studied' (Glaser, 2008, p.9). The constant

comparative method facilitates achievement of a complex theory representative of process, sequence and change related to the area studied.

Theoretical sensitivity is where the researcher interacts with the data in a less descriptive and more analytical manner. Questions are asked about the data and comparisons are made looking for similarities and differences in incidents (Birks & Mills, 2011). Theoretical sampling is used as part of constant comparative analysis. This is an iterative process that is reliant on use of memos. It is the part where the properties and dimensions of categories evolve (Evans, 2013). Memos provide an audit trail of decisions made for the researcher to refer back to as the GGT process progresses and a theoretical perspective develops (Simmons, 2011). Theoretical saturation occurs when data analysis produces codes that only fit in existing categories and these provide sufficient explanation in terms of the properties and dimensions of the category (Birks & Mills, 2011). Theoretical saturation is reached when sampling and coding of data reveals no new categories and instances of variation for existing categories cease to emerge (Bryant & Charmaz, 2007). However, Glaser & Strauss (1967) point out that grounded theory is always provisional and theoretical saturation may not be achieved.

Delimiting the theory occurs as part of constant comparative analysis. This leads to the theory becoming more solid as requirement of modifications reduce as the researcher compares the next incidents of a category to its properties. Eventually modifications are only required to clarify the logic and properties, integrating and elaborating on the properties that provide the overview of the inter-related

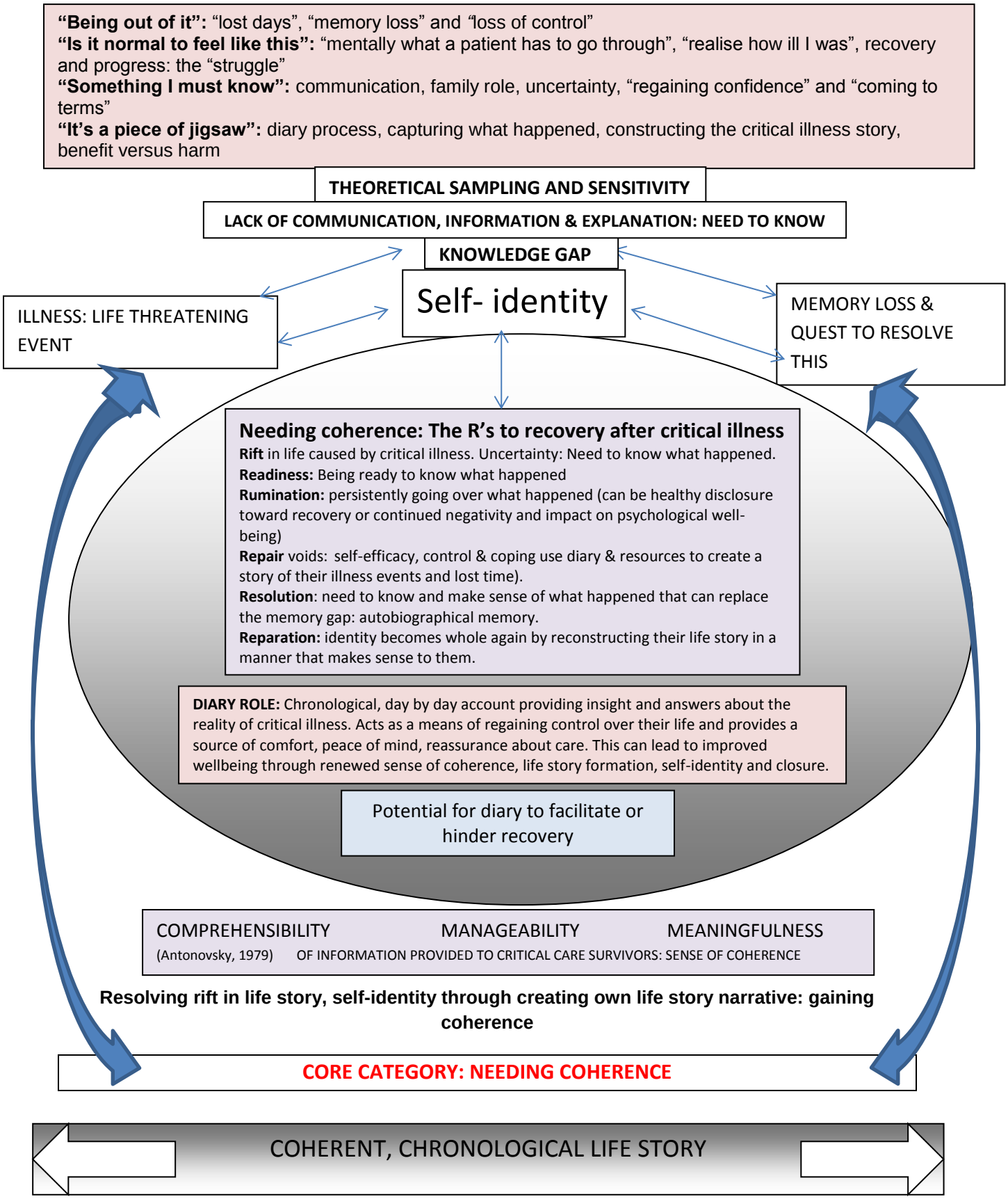
categories. Reduction occurs, thus ensuring only the salient aspects or higher level concepts remain as part of the theory (Glaser, 2008).

According to Glaser (2012) the grounded theory needs to make sense to those reading it; be that researchers or laymen. It should work and provide relevant predictions, explanations, interpretations and applications. It should have practical relevance and therefore enable HCPs to use the theory to understand and have some control over those situations.

8.2 Conceptual map of the emergent grounded theory

Figure 11 p.251 below provides a conceptual map that outlines the discovery of the grounded theory in the current study. The initial box refers to the conceptual categories and associated codes that lead to emergence of the core category: needing coherence. A brief overview is provided in the conceptual map of the factors that influence the theory as elicited through theoretical sampling. In needing coherence the conceptual category chapters identified some key aspects associated with participants endeavours to recover following their critical illness. The relationship of all the factors that form the conceptual map for the discovery of the grounded theory outlined in figure11 below will be explored further in terms of existing substantive theory, conceptual models, empirical and scholarly literature.

Figure 11: A conceptual map of the discovery of the emergent grounded theory



8.3 Relationship of the emergent theory to existing substantive theory, conceptual models, empirical and scholarly literature

The process leading to the identification of the core category and emergent theory using theoretical sampling and theoretical sensitivity is explored sequentially below (from the top of the conceptual map downwards) following the conceptual map figure 11 p.251.

8.3.1 Conceptual categories that formed chapters 4-7

This section will briefly explain the relationship between the conceptual categories and the emergent theory. Further detail related to the emergent theory will be explored as the chapter progresses.

Chapter 4: *"Being out of it"* identified participants' perception of the rift in the normally continuous uninterrupted timeline of their lives. Their sense of self-identity was embedded in being able to account for this missing period. Therefore needing coherence emerged as central to participants' concept of themselves as a person. Although they could not remember the critical illness events, they wanted to know what happened and this is where the diary could play a part in their recovery process.

The issues of a rift or disruption to the normal life timeline and impact on self-identity and coherence is explored further later in this chapter as part of the emerging theory.

Chapter 5: Recovery: *"Is it normal to feel like this?"* participants asked a lot of questions seeking answers about what happened to them. They questioned how they should feel, seeking reassurance that others have felt that way. They ruminated focusing on the source of their distress, causes and consequences rather than on solutions (Smith & Alloy, 2009). Rumination and worry are linked to anxiety, panic and depression (Nolen-Hoeksema, 2008). Participants needed coherence about what had happened during their critical illness in order to understand the reality of how ill they had been. Pivotally they expressed needing coherence about the physical and psychological ramifications.

The issues of recovery and impact of healthy or unhealthy rumination and coherence will be explored later in this chapter as part of the emerging theory.

In Chapter 6: *"something I must know"* participants identified their need to seek answers because communication about what happened to them was lacking. This led to problems in ascertaining a coherent storyline. Most participants were determined to find out and resolve the issues regarding rift in their life, self-identity, loss of control, physical and psychological health: thus needing coherence.

The issues of resolution, communication and needing to know what happened and coherence are explored later in the chapter as part of the emerging theory.

In Chapter 7: critical care diary: *"it's a piece of jigsaw"* participants described a process of reparation where they described needing to know what happened and how they hoped reading the diary could help them to repair the rift critical illness created in their lives, through capturing what happened to them and helping them to construct their illness story. Potential benefits and harm associated with diary use was explored. Repairing the disruption in their life, through coherence, was pivotal and integral to participants' self-identity.

The issue of being ready to know what happened: readiness, reparation and needing coherence are explored in chapter 8 as part of the emerging theory

The next factor to be explored on the conceptual map is in relation to lack of communication, information and explanation and knowledge gap, which were identified in chapter 6 and links to the core category explained on page?, because it is integrated in knowing and understanding what happened to be able to gain coherence about their illness and to repair the rift that has occurred in their life story.

8.3.2 Lack of communication, information and explanation: needing to know what happened

Participants shared concern about the communication process and lack of opportunities to discuss what happened to them with HCPs. This greatly impeded participants' sense of coherence throughout their recovery.

The Picker Institute (2008 p.78) compiled a patient-centred guide, which highlighted from patient experiences the importance of effective communication of information by HCPs. They argue that patients base their perceptions of HCPs on the way they interact and therefore communicate with them. Patient surveys identified that poor communication negatively impacts on patients resulting in 'increased anxiety, vulnerability and powerlessness.' Picker state that there is a 'difference between communicating to patients and families and communicating *with* them.' HCPs intent for communication is based on the objectives to 'help, support and provide care.' However meeting these objectives require undivided attention and an ability to listen to what the patient says. Often there are time constraints and other pressures that undermine the communication process. In the current study there were missed opportunities for facilitating communication and offering clarification.

According to Street *et al*. (2009) communication can be improved using communication pathways to facilitate this in a more effective manner. They describe indirect and direct paths of communication to achieve improved health outcomes. They describe the function of psychosocial health as promoting positive beliefs and feelings by reduced worry, anger, anxiety, fear and despair. This can be achieved through provision of appropriate information and support; communication where the patient feels known, validated, hope, worthy, reassured and comforted.

Suhonen *et al.* (2005) conducted a Finnish descriptive survey study using questionnaires (*n*=928), identifying that information provided in hospital did not

correspond with patients' information needs. The study findings identified that patients' information needs were highest regarding their health-illness and diagnosis (83%, *n*=890), examinations and results (77%, *n*=891) and procedures and treatment (74%, *n*-889). Patients (40%) wanted information about rehabilitation and (37%) about aftercare. Poorest information provided pertained to management of daily life, aftercare and rehabilitation. They conclude that HCPs need to put more effort into eliciting and recognising patient's needs and readiness for information.

A lack of effective communication strategies with critical care survivors were evident in the current study. The diary was a useful resource for some to refer to during their recovery, but for others their knowledge gap about what happened was not resolved. This was because their diary was too brief and follow-up to discuss their critical illness with HCPs was not provided.

Needing to know what happened was an important aspect of the emerging theory. Hupcey & Zimmerman (2000) carried out a grounded theory study comparing intubated and non-intubated critically ill patient experiences using unstructured interviews with 14 participants. They stated that patients who have been critically ill present with differing ability to recall memories of their experience. They propose that some patients have unpleasant memories and that not knowing what happened to them can exacerbate these. They explored knowing, not knowing and the process by which knowing occurs. They identified the need to know at two phases during and after critical illness, which were shared by intubated and non- intubated patients.

They concluded that critically ill patients retain a need to know throughout and after their experience. This needing to know was replicated by participants in the current study. Table 11 below outlines Hupcey & Zimmerman (2000) findings and how the data from the current study potentially develop their theory further:

Table 11: Need to know as identified by Hupcey & Zimmerman (2000) with additional information from current study

The need to know during (Hupcey & Zimmerman, 2000)	**The need to know after (Hupcey & Zimmerman, 2000)**	**What data from the current study adds**
Needing information	Needing information about what had happened	Assumptions are made by staff about what patients know. More information, explanation and communication is required throughout process: Family plays the central part in this process. However not all families can face revisiting the events as it has been traumatic for them so they are not always the best source to fill in missing time. The diary plays a part in filling in information, but in a different way: Reassurance about being cared for as a person. Can be honest, but can also 'gloss over' information. **Memory loss, lost days**
Needing to be orientated	Piecing together events	Sense of coherence: a need to try to form a chronological story of the missing part of their life as memories are what make us who we are and gaps trouble people. **Being ready to know. Need to know and coherence of life story & identity**
Having confusing preconceptions		the blurring of reality with surreal thoughts **Uncertainty, loss of control**
Conclusion: Nurses need to address this need for constant reorientation to past and present in these patients.		A lay summary of events could be a useful addition to the diary and a tool to inform staff in wards or if readmitted about what the patient has been through.

Hupcey & Zimmerman (2000) provided the first two columns in Table11 above. Based on the data from the current study an additional column has been added to demonstrate which findings form the current study can continue to build on the study findings presented by Hupcey & Zimmerman (2000).

Strahan & Brown (2005) stressed the importance of explanation, support and encouragement to understand events. This is also evident in the work by Engström *et al.* (2008) who proposed that patients need to know and understand what they have been through as a means of moving forwards with their lives.

In terms of theory development needing to know and needing coherence are intertwined in aiding repair of the rift in life story following critical illness. It is important to note that not all patients may want to know what happened and this is where the use of a critical care diary requires careful consideration. HCPs need to be prepared that some patients will cope by not choosing to find out more about their illness than they can remember. In terms of recovery not knowing led some participants to ruminate and rumination could be healthy where they seek answers or become unhealthy where patients find themselves in a cycle of questioning that has a detrimental impact on their mental health and wellbeing.

Following on from needing to know what happened the next section puts this into context with the life threatening nature of participants' critical illness.

8.3.3 Illness: life threatening event

As highlighted in the previous section participants expressed a need to know what happened to them. Participants struggled to comprehend the reality of their life threatening illness. Deacon (2012) highlighted for critical care survivors that survival

itself is just the beginning of recovery. The life threatening nature of admission to critical care and the psychological impact that this has on critical care survivors is potentially seen as the root cause for development of PTSD (Griffiths *et al.,* 2008). Arguably effective communication alongside appropriate support during recovery could play a significant role in patients' psychological well-being (Rattray, 2013).

Descriptions of existential/ spiritual concerns were raised by participants in the current study in relation to the life threatening nature of critical illness. McSherry & Ross (2010) highlighted the importance of spiritual components of the person (mind, body and spirit); its role in recovery following illness: attaining and maintaining health and well-being and impact on perceived quality of life. Whitehead (2003) postulated that existential health requires tangible resources, finding meaning in life events and evaluating elements of 'self'. Fundamentally he says that recognition of existential health *'suggests that individuals possess a capacity to initiate a self-healing process by drawing upon an inner strength resource'* (p.679). Whitehead (2003) seems to be describing human resilience and a personal positivity or determination to overcome illness and he criticises HCPs lack of knowledge and understanding of the importance of using this to improve patient outcome following illness. He suggests that if HCPs assessed existential health it could enhance patient's health and well-being.

Participants shared that they struggled to understand how ill they had been because they could not recall it. This impacted on their ability to make sense of what occurred and accept what happened. As participants gained coherence about events some

participants recognised that they could have died. Interestingly few participants had appointments with their consultant after discharge, which is an additional lost opportunity to connect with the patient, to communicate and acknowledge how ill they have been and to review their progress.

In terms of the theory severity of illness impacted on participants need to find meaning about their lives and also to have acknowledgement of how ill they had been was important to their sense of self-identity through making sense of what had happened to them. Thus it was integral to resolution and reparation as part of participants' recovery process (resolution and reparation are explored later in this chapter.

Memory loss experienced by participants also links to the aforementioned issues above and are explored next.

8.3.4 Memory loss and quest to resolve this

Participants in the current study did not share that they experienced nightmares during or since their critical illness, but they did highlight dreams and hallucinations they felt had been intrusive or troublesome. They discussed them in terms of trying to comprehend what they were about and why they occurred.

Domhoff (2000) believes that coherence and consistency of dreams over time and the inter-relationship with the individuals' life events can only lead to the conclusion that dreams are psychologically meaningful. Hartmann (1998) argues that dreams are not just psychologically meaningful, but they serve an adaptive purpose between emotions and the experience. Cartwright (1986) studied the dreams of women going through divorce and established that dreams are a means of processing and organising emotionally challenging experiences into memory. She found women who were coping well with the divorce showed adaptive dream processes. Dreams were longer, reflected a wider time span and dealt with issues related to self-esteem and control. The conclusion to her work was that increased REM dreams following a stressful event is associated with better adaptation or adjustment to that situation. Therefore REM sleep and dreaming are an aid to emotional adaptation achieved through the integration of distressing memories (Cartwright & Lloyd, 1994).

Hartmann (1998) describes connections between the mind and people, memories and experiences. He says these connections take on a broader context during dreams and form new material following trauma. The process rather than being random is linked to the individuals' emotional concerns which are expressed through the imagery of the dream. Hartmann (1998) suggests that following trauma the dreams form a way of processing and possibly dealing with the experience moving from accurate replay of the trauma and reflecting the progression of emotions such as fear, guilt and grief.

Participants' perception of amnesia, despite some sharing glimpses of memory during interviews, was significant. Dissociative amnesia can occur in response to a stressful or traumatic event and manifests itself because the individual blocks out their memory of that event. The memories exist, but are hidden away and can sometimes re-emerge if triggered by something related to the original trauma. Dissociative amnesia as a protective mechanism could provide an explanation for participants' perceived amnesia as it results in disruption to memory, consciousness, awareness, identity and or perception. An individual cannot remember something experienced if they did not know that they had explicitly experienced it. This has been identified in amnesic studies (Rosenbaum *et al*., 2005).

The construction of an individual self-history or autobiography is a way of explaining to oneself why things happened in the way they did and their significance for present day. It needs association in place, time and social context. It allows planning for future life and goals. Reminiscing or sharing our past with others is vital to autobiographical memory and generally forms a way of showing our personality and characteristics through explaining these meaningful events in our lives (Berntsen *et al*., 2003).

Trauma related stress can lead to nightmares, which are associated with the minds attempt to make connections between recent events and past memories with the aim of integrating old and new information and experiences. During sleep the brainstem produces a mixture of images, memories, thoughts and emotions, leaving the cerebral cortex to try to shape this into a coherent story. It is the forming of the story

that is thought to help the person to think through experiences and find solutions or consequences that they would not otherwise have confronted. Perhaps then, the significance of the hallucinations, dreams and nightmares that critical care survivors shared during the current study are actually their way of trying to make sense of what has happened to them (Berntsen *et al*., 2003).

In terms of the theory, data indicated that the experiences related to *"being out of it"* explored in chapter 4 were traumatic and memory loss and needing to know what happened to gain coherence over events that occurred was important to most participants and linked to repair during recovery through seeking coherence via resolving missing information.

The next section explores self-identity as this was affected by the memory loss and sense of detachment participants felt as a result of their critical illness experiences.

8.3.5 Self-identity

Participants' sense of who they are (self-identity) is affected by the rift in their concept of their life story timeline.

In the American Psychiatric Association Dictionary of Psychology (VandenBos, 2007, p.541) identity is:

> ‘*an individual’s sense of self defined by a set of physical and psychological characteristics that is not wholly shared with any other person.’*

Sense of self is defined as *‘an individual’s feeling of identity, uniqueness and self-direction’* (p.542). Existential concerns have been attributed to two main themes in cancer care around the struggle to maintain self-identity and the threats to self-identity (Henoch & Danielson, 2009, p.227). In the case of participants in the current study, their self-identity has been disrupted by the period of unconsciousness and vulnerability of the life threatening nature of their illness. The subsequent threat to their self-identity manifests itself through their descriptions of perceived amnesia of their critical care admission and the rift this memory gap has left in the timeline and therefore coherence of their life story.

Illness impacts on physical well-being and psychosocial functioning and intrudes on the way we perceive ourselves (Sitvast & Abma, 2012). Illness that becomes chronic impacts on the person in the sense of social expectation, rules and identity (Kleinman, 1988). Gergen (1994) identified that the way in which a person perceives themselves (identity) is dependent upon the reaction they get from others. This process entails finding answers to why this illness has affected them, what the cause may be and how they can control the illness. All of this requires coming to terms with experiences, overcoming fear and anger and restoration of confidence.

Strauss & Glaser (1975) used grounded theory to understand the meaning of illness for both those suffering from chronic illness and their families’ perspectives.

Uncertainty in illness involves the issue of not knowing what to expect as a result of the illness (Strauss & Glaser, 1975, p.175). Gecas (1982) considers self as both a process and an object. According to Charmaz (1999, p. 366) self as a process leads to *"unfolding, developing, and becoming".* Self as object can be interpreted as the "*attributes, sentiments, values and characteristics"* that people use to define themselves.

Charmaz (1999, p.365) notes a sudden disjuncture between past and present; emphasising the extent and depth of suffering. She uses drug changes or medical review as examples. Whereas in the case of the current study the disjuncture took the form of an awareness of missing time from their lives and the rift that this incurred, affecting their self-identity and resulting in a need coherence.

McAdams (2004) proposed the life story model of identity. He stated that people living in modern society organise their lives through self-stories. They reconstruct their past and visualise their future via internalised and evolving life stories. This aspect has been disrupted in the case of the participants in the current study.

According to McAdams (2004, p.100) peoples identity is grounded in the form of a story complete with 'setting, scenes, character, plot and theme'. This life story cannot cover every single detail of the individual's life, but can capture the significant and prominent scenes encountered. This means it is a subjective and selective process with meanings and values related to those scenes being dependent on individual

perceptions. McAdams argued that no two life stories will be the same even if they include the same events occurring at the same time period. It is the commonalities found in the themes from each story that makes individuals comparable. The crux of McAdams (2004) life story model is the belief that identity is a life story, which is always evolving and the rationale for a life story being constructed by individuals is to have psychosocial unity and purpose in modern society. McAdams (2004) stated that the life story themes would be those felt significant and selected by the individual. Provision of a diary could contribute to participants missing timeline by capturing what happened in a chronological day by day manner. Equally if there are gaps for dates, it could fail to capture enough that is felt to be significant by the participant.

When a person remembers an event in which they participated, they are normally thought to be aware of the event as veridical, meaning truthful or coinciding with reality (or sometimes non-veridical) (Oxford Dictionary Online, 2014). What we have done in the past becomes part of our self and the ability to reflect influences our behaviour in the now (Gergen, 1994). In psychology the self represents a set of attributes that a person attaches to themselves: identity. In philosophy self is the agent, knower and focus of personal identity (Dowling, 2011).

Fivuish & Haden (2003) argued that in psychology it is accepted that self and autobiographical memory work in tandem, but the relationship remains to be explained. They also proposed that emergent theory about the role of narrative in human cognition surrounding the construction of a life story based on the

interconnection between memory and self. A consensus is shared in their book that people create a life narrative based on socio-cultural frameworks thereby defining what is appropriate to remember, how it should be remembered and what it means to be ‘self with an autobiographical past’. The role played by narratives in autobiographical memory and memory, narrative and self is complex. They argued that although events occurring in the world are organised in terms of space and time that narrative formation is what enables events to be adapted to a form that reflects human meaning (Dowling, 2011).

Narrative allows complex organisation and understanding of the events experienced through facilitating subjective evaluations of what happened through development of themes and their relationship to time and space that become linked by personal meaning making, such as family perspectives and other sources of information sharing (Fivuish & Haden, 2003). The way adults share their memories with others leads to modulation of the way those experiences are interpreted through that social interaction and thus shapes self-perception and identity and understanding of oneself (Pasupathi, 2001).

Through narrating an event it gives it context of time and place, provides central action or goal, motivation and highlights surprise, success or failure, shares emotions connected to it and provides a conclusion and evaluation. Verbalising the story organises the experience and provides a rationale for remembering it as significant, be that personally or socially. It is this personalised memory reconstruction process that enables individuals to share memories or to retain them

for themselves which constitutes formation of autobiographical memory and preserving of memory over time (Fivuish & Haden, 2003). The point of these processes has been linked to functional systems and development of cognitive control, where the individual draws on memory to predict their response or actions to a situation they face: the past informing the future (Fivuish & Haden, 2003).

Illness experiences need to be put in a chronological order forming a personal story that accounts for the 'onset, continuation and exacerbation or recovery' from illness over time, to aid the forming of a coherent personal story (Sitvast & Abma, 2012, p.178). Meaning making from forming illness narrative demonstrates how patients 'struggle for authorship of their lives' and in finding resolution patients can portray increased 'sense of self-efficacy' (Sitvast & Abma, 2012, p.178).

All of these previous sections that emerged from the conceptual categories led to theoretical sampling and sensitivity identifying the following: rift, readiness, rumination, repair, resolution, reparation are all part of patients recovery process and regaining of coherence, control and self-identity after critical illness. These are explored in more detail in the next section.

8.4 Needing coherence: The Rs for recovery after critical illness

The conceptual map figure 11p.251 incorporates a table that identifies key aspects highlighted in the conceptual category chapters that link in an overlapping rather than sequential manner: Needing coherence: The Rs for recovery after critical illness

and these aspects are incumbent in participants' descriptions of their recovery process and diary use. These emerged from the conceptual categories and associated codes in chapters 4-7.These factors have been analysed in further depth to inform development of the substantive theory figure 12 p.304.

Table 12 Needing coherence: The Rs to recovery after critical illness

Needing coherence: The Rs to recovery after critical illness
Rift in life caused by critical illness. Uncertainty: Need to know what happened. **Readiness:** Being ready to know what happened. **Rumination:** Not knowing: persistently going over what happened (can be healthy disclosure toward recovery or continued negativity and impact on psychological well-being) **Repair** voids: self-efficacy, control & coping. Use diary & resources to create a story of their illness events and lost time if it is perceived by the critical care survivor as addressing their need to know (content, chronology and coherence impact on this). **Resolution**: need to know and make sense of what happened that can replace the memory gap: autobiographical memory. **Reparation:** identity becomes whole again by reconstructing their life story in a manner that makes sense to them.

The Rs to recovery after critical illness are not a chronological process. Indeed they interlink and overlap throughout patients' recovery (Table 12 p.269 would be handed out in conjunction with the substantive grounded theory figure 12 p.304 and key components of the diary role and purpose table 15 p. 308). The following sections will address each aspect noted in the Rs to recovery after critical illness.

8.4.1 Rift in life

Experiencing critical illness and lacking memory leads to a rift in the participants' comprehension of their lives. As the critical illness event has been life threatening

this inevitably leads to questions about their life and its meaning, uncertainty and needing to know what happened.

Bamberg (2010) proposes that life stories are not necessarily fixed and are determined by the purpose for which the story is being told. He argued that maybe the actual events are not important, but it is about what they stand for such as how they connect with other events and how they differentiate us as special or unique or every day and mundane. This relates to the findings of the current study in that participants sought a comprehensive, coherent and chronological overview of their critical illness story to help them resolve the rift in their life story, self-identity, and to aid their recovery by helping them to address disruption and find coherence.

As humans we have the ability to mentally place ourselves in the past or future or counterfactual situations and to analyse our own thoughts. Our sense of self affects our behaviour in the past, present and future (Horsdal, 2012). According to Horsdal (2012) plausibility is important to people in forming their life narrative. This means that the diary content needs to seem reasonable or probable to the reader. If not it could be a further source of confusion. The participants in the current study draw on threads of information about what happened to construct a story for their missing time that makes sense or is plausible and has meaning to them. In Emily's case her husband proved to be able to tell her more than her diary, but she was left unsure what had actually happened to her and was unable to query this afterwards. While others like Alice, Beth, Clara, Fran and Graham found their diary did help them find

some coherence to events, even if this included family discussions as well as diary use.

The rift in their comprehension of their normally chronological timeline of their lives experienced by participants is not unique. Concurring with this concept, Bury (1982, p. 169) argues that illness results in people experiencing a situation where the *"structures of everyday life"* and *"forms of knowledge which underpin them are disrupted"*.

Bury (1982) describes three aspects to disruption in chronic illness. Firstly, disruption of taken for granted assumptions and behaviours (What is going on here stage), this incorporates awareness of bodily states people are not usually conscious of. In the current study participants referred to losing trust in their body and the need to regain confidence in their health to aid their recovery process. The difficulty was in understanding what they had been through so that they could be better prepared for what their recovery entailed. Secondly, disruption to explanatory systems, like a rethinking of their biography and self-concept.

In the current study, participants had difficulty in comprehending their life and existence during the time they were unconscious. Thirdly, there is a response where people face the altered situation by accessing resources available to them. In the current study participants sought information from family members, HCPs and their diary in order to validate what happened to them and to understand how ill they had

been. Biographical disruption plays is an important part in participants' critical illness journeys in the current study. They identify their need for coherence in their life story and integrated in this is their sense of self-identity.

According to McCormick (2002) uncertainty forms a large element of patient's illness experience and is linked to problematic psychosocial adaptation and illness outcomes "When one does not know what the future holds, or how much time will be required until the ambiguity, unpredictability, or vagueness of a situation is clarified, then uncertainty prevails" (McCormick, 2002, p.130).

Hilton (1992, p.70) defined uncertainty as *"a cognitive state created when an event cannot be adequately defined or categorised due to lack of information"*. According to McCormick (2002) uncertainty is linked to problematic psychosocial adaptation and illness outcomes:

> *"When one does not know what the future holds, or how much time will be required until the ambiguity, unpredictability, or vagueness of a situation is clarified, then uncertainty prevails" (McCormick, 2002, p.130)*

Mishel (1988) based her tool for assessing uncertainty on situational experience of illness: ambiguity, complexity, deficient information and unpredictability and asking patients to rate how uncertain they are about specific illness situations. Whereas Hilton's scale (1992) asks patients to rate both uncertainty in illness situations and the stress they believe they experienced and therefore try to capture an emotive response to the situation. In the context of the participants in the current study both

tools would have applicability. It is the emotional impact of uncertainty or what participants refer to as “not knowing” that can negatively or positively affect their recovery depending on how self-motivated and determined they are to find answers. Uncertainty can lead to anxiety in relation to a loss of control over the critical illness event, memory of it and what the future holds as a result.

Acute health crisis with potential chronic illness and disability (CID) is known to impact on individuals lives through confronting ensuing physical debility, on-going treatment requirements, psychological distress and the uncertainty that the illness causes. It is argued that some individuals cope well, finding a new life balance and renewed appreciation of life; whilst others struggle to cope and encounter psychological consequences manifesting as anxiety, depression or panic and in some cases even PTSD (Moos *et al.,* 2007, Kress & Herridge 2012).

Charmaz (1999) pointed out that suffering in chronic illness can lead the individual to resolution and new wisdom or depression and despair. Loss of control over health can include loss of control over the body and autonomy, which replicates what participants shared in the current study and as previously mentioned in chapter 4. Additionally, uncertainty arises when individual’s future is no longer as they perceived it to be because their illness and prolonged recovery makes their health an unknown entity (Gecas, 1982).

In the current study participants recovery process was affected by their inability to relate to the life threatening event. They sought coherence through information gathering from sources available to them, which included their diary. Discovering what happened and piecing their story together was integral to their recovery process. It formed part of coming to terms with it, acceptance and facilitated the process of moving onwards with their lives.

In the case of participants control was regained over their life, through knowing what happened: gaining coherence, self-identity and resolution during recovery.

8.4.2 Readiness: Being ready to know

Participants described issues around being ready to know what happened to them and this was explored in chapter 7. Discussions from chapter 6 about “something I must know” which was a quote from Alice at two months and the concerns raised about being ready to face what happened raised by Emily and Clara demonstrate that participants coped in different ways with their critical illness event.

There is a difference between being prepared and being ready. This difference is that being prepared requires an action to be taken beforehand; while being ready requires the person to be psychologically able to do something: emotional readiness (Doka, 2014).

According to Corr (1993) an individual can decide on any day what they choose to do, or not. Similarly in life threatening illness the patient can choose, or not to confront the challenges related to that. According to Corr (1992) patients will find individual and idiosyncratic ways to resolve issues in related to confronting, or not their life threatening illness. In the case of the current study participants have been through a life threatening event, but are not living with a potentially terminal disease. However, the similarities are that participants dealt with the psychological issues related to what has happened to them.

The phases of life threatening illness outline the peaks and troughs of anxiety in relation to acute, chronic and terminal illness Doka, 2015, p.6). The highest incidence of anxiety peaks occurs in the chronic phase of the illness trajectory. This has a direct correlation with the chronic impact of critical illness on participants during recovery in the current study. ICU survivorship has already been discussed in chapter 5 where the chronic psychological and physical debility associated with being a critical care survivor has been described as an increasing concern (Rattray, 2013).

Coping with anxiety and uncertainty are integrated within concerns of patients suffering life threatening illness; as they are with participants who survived critical illness. In the chronic phase of illness patients are trying to live a normal life within the restrictions posed by their illness. The impact of illness and uncertainty has been discussed in the previous section (Charmaz, 1999). Rehabilitation strategies have

been linked to improved quality of life and adjustment to illness situations (National Cancer Survivorship Initiative, 2015).

Patients with life threatening illness sometimes use denial to cope with the reality of surviving everyday life. This is a way of not constantly focussing on death (Doka, 2014, p.21). Similarly for participants in the current study there is evidence of this coping strategy (denial/avoidance) in Emily. External cues, such as the way people look at them and family behaviour and actions can be unwanted reminders that disrupt their coping strategy (Courtois & Ford, 2012). This was evident in Emily's description of her husband and friend talking. In trauma patients who have survived there is a sense of foreshortened future and hopelessness about having a satisfying life and this came through in both Emily and Fran's quotes. Trauma survivors can become passively entrenched in victim mode or chronic disempowerment (Courtois & Ford, 2012).

Participant's readiness to know what happened was of pivotal importance. It is not advisable to make someone confront something if they cope better by not knowing. This is where patients need freedom of choice to accept or reject the diary. Also the diary process needs a support mechanism within it to support patients beyond handing over the diary. The psychological ramifications are potentially significant where a diary is handed over to be read potentially alone with no follow-up support in place.

8.4.3 Rumination

Rumination is defined as ‘a deep or considered thought about something’ (Oxford dictionary online, 2010). Rumination is perceived as the individual demonstrating a focus of attention on their symptoms of distress. They constantly question the possible causes and consequences rather than considering solutions. Thus rumination and worry are often seen in tandem, being linked with anxiety and other negative emotional states (Nolen-Hoeksema *et al.*, 2008).

Fundamentally when an individual ruminates their aim is to find answers to questions: How do I feel about this event? How can I change my thoughts and feelings about it? How can I prevent disturbing thought and feelings in the future? (Matthews & Wells, 2004). It has been identified that in answering these questions those who ruminate will focus on their emotions rather than finding solutions and identifying goals to act upon (Watkins, 2004).

Response Styles Theory (RST) has demonstrated that rumination is linked to development, maintenance and aggravation of depression and a whole host of negative emotional states (Smith & Alloy, 2009). Positive distraction is seen as a healthy alternative to rumination, but is also perceived to be a limited strategy (Watkins, 2004). The self-regulatory executive function model (S-REF) of affective dysfunction contends that rumination can be explained in a multi-level model of self-regulation that requires meta-cognition. It is feasible that in the case of some participants that their ability to rely on meta-cognition has been disrupted by their

period of unconsciousness and lack of memory as a result. They are already struggling to comprehend and gain coherence. As they are vulnerable to psychological issues perhaps rumination of the unhealthy kind is more able to emerge.

According to Watkins (2004) rumination after an experience can have both maladaptive (conceptual-evaluating mode) and adaptive (experiential mode) consequences on recovery after traumatic events. Dwelling on a problem tends to lead to depression (Nolen-Hoeksema *et al.*, 2008). Watkins (2004) also found expressive writing did help patients overcome rumination, which may hold value in light of Ewens *et al.* (2014a) visual diarising, where critical care survivors construct their own diary about their critical illness during their recovery, using images which they feel capture their feelings and writing about them.

Healthy self-disclosure is posed as beneficial in the right conditions and can reduce distress and rumination when greater insight and understanding about the problem is achieved (Pennebaker, 1989). Sharing feelings with family and others can lead to personal growth. Dwelling on a problem tends to lead to depression (Nolen-Hoeksema *et al.*, 2008). Watkins (2004) also found expressive writing did help patients overcome rumination, which may hold value in light of Ewens *et al.* (2014a) visual diarising, where critical care survivors construct their own diary about their critical illness during their recovery.

When women are depressed they are more likely to ruminate, while men tend to distract themselves (Nolen-Hoeksema *et al.*, 2008). This belief was used to explain the higher rate of depression in women than in men (Nolen-Hoeksema, 1987). Strauss *et al.* (1997) dispute the accuracy of this and claim that rumination can equally impact on both genders. In the context of the current study there was an imbalance in gender which favoured women and therefore results potentially reflect this disparity.

The American Psychiatric Association (APA) DSM-5 (2013) includes rumination as part of the symptoms of PTSD. In this context, critical care diary use needs careful application with supportive mechanisms in place. Focusing on bad things that happen in order to make sense of them is linked to poor psychological health and loss of a sense of control over events and subsequently anxiety and depression (Nolen-Hoeksema *et al.*, 2008). Goal progress theory (GPT) sees rumination as part of goal progress and individuals who have goal related information easily available to them are most likely to ruminate (Watkins, 2008).

Therefore based on the premise of Goal process theory provision of a diary and information about their illness could in effect be a counterproductive measure. Careful consideration needs to be given to whether a critical care diary can potentially trigger rumination or if it can act to quell it. A diary can therefore potentially help or hinder a patient's recovery and must not be construed as purely beneficial in all cases.

8.4.4 Repair voids

Provision of a diary has been described as a resource for some participants (Jones, 2009a), but not all; because it is dependent upon the content and completeness of the story for the patient for whom it was meant. In terms of recovery the diary can play a part in facilitating patients regaining of control over the missing pieces of their life.

Self-efficacy is the belief that one has the capabilities required to undertake and complete a course of actions that are necessary to manage a given situation. Improvements in health outcomes have been reported when self-efficacy has been recognised and supported (Lorig *et al.,* 2001). However it appears from the participants' experiences that they were not provided with the necessary knowledge understanding and skills to be able to achieve self-efficacy.

Lau-Walker (2004) looked at cardiac patients in a cross sectional study and the relationship between illness representation and self-efficacy. This study also linked findings to cardiac rehabilitation programmes. In order to cope with illness events it has been noted that it is important to look at patient's everyday beliefs and strategies for coping with health threats. The self-regulatory model (SRM) of illness is based on five components: identity, cause, timeline, consequences and control/cure (Leventhal *et al*., 1984). This model can be used as a framework to predict a patient's capacity to cope. Interestingly the components reflect key aspects that are fundamentally compromised for participants in the current study.

According to Schwarzer (1992) humans function through personal sense of control and their use of action to problem solve plays a fundamental part. Self-efficacy is the term given to this personal action or control. Individuals with a low sense of self-efficacy are most likely to present with symptoms of anxiety and depression and helplessness. There is also a pessimistic tendency aligned to these individuals. Individuals with high self-efficacy are most likely to choose to face challenges in life, set themselves higher goals and achieve them. Through their optimistic attitude they are more likely to invest time and effort and try for longer.

Some research has associated personality as a determinate of a person's resilience. However, this is seen as a controversial point with Mishal (1988) identifying that personality had little influence. Positivity is seen as improving resilience with negativity and rumination about the event reducing coping and resilience (Bonnano *et al*., 2011). Myhren *et al.* (2010) considered personality and optimism versus pessimism as predictors for psychological problems in critical care survivors. Optimistic personalities tend to cope differently with their illness and this is associated with a quicker course of recovery, they suffer less psychological problems and have a better quality of life (Schou *et al*., 2004, Myhren *et al*., 2009).

Revenson (2003) has explored how individuals and their spouses cope with stressful events. Fundamentally when one spouse is ill it impacts on the family as a whole. Coping in intimate relationships is described as a dual process where the partner of

the spouse who is ill takes on the role of social support and helping them to cope by providing unconditional love and affection regardless of the impact of the illness. They provide a willing listener and advisor, with continuity and security. They share their loved ones existential and practical concerns and meaning of illness issues. However, if the spouse becomes overwhelmed in terms of impact of the illness on their psychological or physical capability or if they are traumatised by events and psychologically vulnerable they will be unable to provide support in the manner expected and this can cause relationship conflict and have a negative impact on coping ability for both spouses. Meier *et al.* (2011) stated that dyadic coping is a form of management of stress through the support of a significant other. The way in which couples dealt with chronic illness had a positive or negative effect on outcome depending on how well they supported each other.

Needing coherence was part of recovery from critical illness for participants to help them address the rift that had occurred in their concept of their lives. Repairing voids also refers to participants need to know and make sense of what happened to them.

8.4.5 Resolution

Resolution is the action of repairing something (Oxford dictionary online, 2017). According to Penrod (2001) facing uncertainty is one way individuals can resolve their sense of loss of control. She believes that cognitive, emotive and behavioural strategies to cope with uncertainty related to illness are integral to the passing of time. This includes the individuals altered perception of events, which can lead to an

interpretation that the individual can contend with; thus having potential to ease illness related uncertainty. This concept of individual perception of events being developed to form an acceptable illness narrative is evident in participants in the current study. Over time data showed that with the use of their diary, participants were able to start to piece together information in conjunction with what family had shared with them. Finding out what happened on the dates that they could not remember was important to most participants. The coherence of the story was important to participants and they expressed concern when there were dates missing from their diary. Final interviews demonstrated that participants had assimilated new knowledge about their critical illness episode and could recant these in the form of a newly formed story.

The continuing resolution of this main concern is accounted for by participants desire to fill in the void in their memory by assimilating information from family, HCPs and their diary: seeking coherence. This knowing enables participants to feel a sense of life story coherence that they had lost during their period of unconsciousness. Integrated within this is participants' reclaiming of sense of self or identity. Participants explained it was difficult to understand what they had been through and how ill they were. It did not feel like reality to them until they read their diary. The diary has potential to give meaning to a significant episode of their lives, of which they felt they had no part.

During their life span most people will experience at least one traumatic event significant enough to meet DSM criteria for psychological trauma (an event that

threatens or causes serious personal harm or injury). Bonnano (2004) suggests that the notion of 'traumatic events' be replaced with potentially traumatic events (PTE's) because there is so much variability in individuals response to loss and trauma. Some feel overwhelmed; others struggle initially then recover, while some appear resilient with no noticeable effect on functioning quite quickly after the event. He defines resilience as "the ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event....or life threatening situation, to maintain relatively stable, healthy levels of psychological and physical functioning" (p.20). PTSD is described as only manifesting in 5-10% of individuals exposed to PTE's, though it is acknowledge that these statistics are variable in research studies (Bonnano *et al.*, 2011). Some research has associated personality as a determinate of a persons' resilience. However, this is seen as a controversial point with Mishal (1969) identifying personality had little influence. Positivity is seen as improving resilience with negativity and rumination about the event reducing coping and resilience in PTE (Bonnano *et al*., 2011).

Puchalski (2001) said that the role of HCPs is to help people find meaning and acceptance during chronic illness. True healing requires answers to difficult questions. Healing is described as an acceptance of illness and peace with one's life. Patients who are spiritual may be able to use their beliefs to cope with their illness, life stresses and recovery from illness seems to be enhanced. When done well a critical care diary can provide insight and answers about what happened and the reality of their illness for critical care survivors. The use of a patient diary can facilitate 'peace of mind', 'comfort', sense of ''control' and 'closure' according to participant data shared in the current study.

HCPs who wish to contribute to patient diaries need to have knowledge and understanding about its potential use, benefits and harm in order to construct a comprehensive, chronological overview that provides a meaningful story of the critical care journey that provides its owner with a sense of coherence for their missing time.

8.4.6 Reparation

Reparation means to repair or restore and is a part of the interlinking processes participants went through in order to repair the rift in their life story, self-identity and needing coherence during their recovery (Oxford dictionary online, 2017).

According to Iwashyma (2010, p.204) critical care survivors are an increasing population who on discharge from hospital are abandoned to face *"the challenges of critical illness survivorship."* This is an often complex and daunting journey with *"burdens and legacies"* associated with surviving a life threatening event. Studies in relation to cancer have demonstrated that after a life threatening event individuals may reflect on their mortality, spirituality, meaning and purpose in life. Trying to find reasons behind what occurred and to make meaning from the illness (Tartaro *et al.,* 2005).

Toombs (1987, p.230) wrote about the meaning of illness and how the concept of body alters after an illness experience, with individuals being left feeling at their body's 'mercy' and that 'at times my body fails me.' She argued that even on return to health individuals retain knowledge that they have 'limited control' over their body and that can be unnerving for individuals. However Delmar *et al.* (2005) studied what it means to live with chronic illness and determined that patients can achieve harmony with oneself. This was achieved through moving towards acceptance, which they described as reconciling themselves with their illness and learning to adapt to living with it. They wrote about the existence of hope for the future, within this discussion they noted patients may move between hope and despair with doubt and that there is healthy hope where individuals are proactive in dealing with their illness legacy and delusion or denial where the individual tries to deceive themselves, preferring to avoid alluding to their problems or reconcile themselves with what has happened to them. Whilst this is written about chronic illnesses it equally applies to the participant data shared in the current study.

According to Houkamau (2008) people organise and make meaning of their lives through the creation of personal histories that involve reconstruction of their past and anticipation of their future. This is done by drawing on events that have happened to them in the past and integrating them in a *"meaningful sequence and use that 'story' to explain who they are, what that means, and where they are 'going'" (p.4).* Personal life stories are described as being the best way to understand how individuals experience and understand themselves in the context of time (Ezzy, 1998).

8.4.7 Recovery

Recovery encompasses all of the apsects mentioned above in the Rs to recovery after critical illness. These aspects highlight the challenge of participants dealing with their life threatening event. It is about trying to find coherence through repairing the rift in their life story and thus regaining their self-identity and control over their recovery. The use of a critical care diary is one way in which information can be communicated to patients about care they have received. Most participants found it helpful in their recovery as reading it enabled them to find reassurance about care their received while they were vulnerable and not active participants in the processes that were occurring to maintain their life. The diary could help participants understand the reality of how ill they had been. Photographs were felt to be important in this process of validating how ill they were. When participants had bad days reading the diary could make them feel more in control again in the sense that they could be realistic about how ill they had been and then accept the limitations associated with recovery after critical illness.

According to Ehlers & Clark (2000) seeking to know and understand the arguably traumatic critical illness events risks incurring psychological or emotional harm to the individual. Harry was the only participant to be adamant that he did not want to know what happened to him in critical care. He was comfortable talking about how he felt, but did not want more than that. Other participants shared their anxiety and even sense of panic related to their life threatening illness experience.

Whilst PTSD may occur, the numbers of incidence are difficult to quantify, but when it does manifest in patients or relatives there needs to be a process of referral and support in place. Bisson *et al.* (2013) in their systematic review on PTSD in adults found that Trauma Focused Cognitive Behavioural Therapy (TFCBT) and eye movement desensitisation reprocessing (EMDR) should form the first line treatment. However, in order to access such support, symptoms need to be recognised and service provision needs to be in place for appropriate referral or self-referral if that works better.

The need for information and communication was important to participants as they drew the threads together to form a coherent story about their missing time. The diary played a part for some and not so much for others and its value remains to be determined alongside the potential for harm, not just benefits.

8.5 Diary role in recovery from critical illness

The key rationale for use of a diary appears to be related to the provision of a means of capturing events during the patient's stay and therefore providing a source for patients to try to understand gaps in their memory while critically ill in intensive care. Egerod & Christensen (2009) in the findings of their study describe the base narrative of illness as having three stages: crisis, turning point and normalisation and containing parallel plots of the nurse, patient and family storyline. The stages of narrative and parallel plots they identified are outlined in Table 12 below with the potential contribution from the current study added in red.

According to Egerod & Christensen (2009), diaries provide a means of construction, reconstruction and narration of stories. They describe the diary narrative as having a 'plot' forming a restitution narrative, detailing the journey from health to sickness and recovery. They also note a chaos narrative describing life improving after illness and finally a quest narrative where illness forms the trigger for life changes. The data from the current study have been added below in Table 13 to demonstrate further contribution to knowledge from existing theory development by Egerod & Christensen (2009).

Table 13: Addition of data from the current study to work by Egerod & Christensen (2009, p.272)

Stages of narrative	**Parallel plots**		
	Nurse's storyline	**Patient's storyline**	**Family's storyline**
Crisis	Active, focus on technology	Passive, depersonalised Loss of control Being ready to know	Spectator, worried Active experiencer Protector
Turning Point	Shifting focus to caring interventions	Emerging, Loss of control as unconscious Vulnerability Dignity & privacy Repersonalised: Possibly not true until after discharge, home. Lost & confused with uncertainty and lack of validation of how ill they were. Information to aid in gaining coherence leads to insight into illness and recovery.	Engaging, relief and gratitude Fear Protection Avoidance of revisiting own trauma about event
Normalisation	**Converging plots**		
	Relating, participating, connecting, letting go this may be cyclical and not a seamless transition, and how patients do this is missing in their article The current study indicates that needing coherence and addressing that so that participants can form their own interpretation or story of what happened is the way in which participants dealt with their critical illness. Repairing the rift in their life story and self-identity		

Table13 demonstrates how data from the current study can build upon the work previously done by Egerod & Christensen (2009). It identifies how some aspects of the patient illness storyline are not fully considered, such as the converging plots and normalising process, which participant data from the current study would suggest is not a seamless process. As identified by Egerod & Christensen (2009), critical care survivors seek resolution about their critical illness and recovery, but they do not explain why this happens. Data from the current study has identified that it is due to the rift that occurs in their normally coherent, chronological perception of their life story. The resolution is gained by effective communication, explanation and provision of information that can be clarified and digested over time. Provision of a diary can potentially help or hinder this need for coherence in critical care survivors' recovery process.

Toien *et al*. (2010 p.1558) argue that making events related to the critical illness experiences 'coherent' and 'factual' actually premeditates psychological distress rather than alleviates it. This is a concern that needs to be considered and it is important that diary use is not imposed on patients and that they are free to decide if, or when they wish to have their diary. Some patients have contacted the study site diary team asking for theirs around the first or second anniversary of their critical illness event. This implies that patients need to be ready to face what happened to them and therefore some may never want it.

8.5.1 Diary role in reparation through constructing the illness story

This section relates to 8.4.6 where reparation was explored. The diary has potential to form a part of the interlinking process of repairing or restoring the rift in their life story, self-identity and needing coherence.

Although subjective, individuals' stories hold meaning. According to Charmaz (1999) telling the illness story may give the person a different perspective on events and self-identity. The story may be shared in a reconstructed form enabling the person to review and re-evaluate their life. The use of a diary may facilitate or hinder patients' ability to form their critical illness story.

> *"By piecing the past together, a storyteller makes sense of the present and future. Stories create pattern, coherence, and sometimes resolution"* (Charmaz, 1999, p.371).

Furthermore, a story about an illness experience can alter with time. It can evolve as knowledge and understanding develops (McAdams, 2004). In Charmaz's (1991) experience the initial story of the illness event may be adapted later in time by the person and presented in a different ways to different audiences.

Williams (2009) found in her doctoral research study that constructing a story after critical illness can benefit patients. However establishing a coherent narrative of events was difficult for patients and help was required to achieve this. Williams

(2009, p. 281) describes ‘dimensions’ that enable a coherent story to be constructed. These are temporal coherence which pertains to the story being chronological. Causal coherence is about the story making sense of events and subsequent consequences.

Pivotally according to Corbin & Strauss (1988) the act of telling an illness story creates continuity for the individual in the face of what have become disrupted lives. The process is a way of understanding what has happened and of coming to terms with events. The evolution of a story plays a crucial part in the individuals’ acceptance of the impact of their illness and as Charmaz said, can lead to resolution.

> “*A story provides a way of making sense of suffering, of locating self in life, and of coming to terms with an altered existence*” (Charmaz, 1999, p.374).

The way in which the story is usually structured provides context and meaning. However, in the case of critically ill patients their illness story is incomplete as a result of *“being out of it”,* which has left them with memory impairment and the sense of *“lost days”* and missing time that they cannot account for in the sense of what actually happened to them. The need for coherence in relation to patients’ experiences of illness is therefore evident in existing literature. Its application to the situation expressed by participants in the current study is important in understanding why they feel the way they do following critical illness.

Sutin & Robins (2008) claim autobiographical memories can be retrieved either from the first person, where the individual sees the event through their own eyes, or third person perspective, where individuals see themselves and the event from the perspective of an external observer. This research fits with use of a critical care diary written vicariously by HCPs on behalf of the patient, forming a third party perspective that participants were able to draw on during their recovery.

Self-representation is essential for a coherent and meaningful life (Lou *et al*., 2004). Consciousness is accompanied by a feeling of continuation and coherence in existence beyond the present, between the past and as prelude to the future: therefore a sense of life coherence in the experiences of life. This can be damaged as a result of traumatic experiences (Horsdal, 2012). We create meaning through a focus on a time span, using narrative skills to intervene in the flow of time and go beyond the present, by connecting with the past, present and future in order to make sense of what is happening. Narrative with a beginning, middle and end is a form of cognition we apply to create meaning and understand life itself (Wheeler *et al*., 2007).

Illness experiences need to be put in a chronological order forming a personal story that accounts for the *'onset, continuation and exacerbation or recovery'* from illness over time to aid the forming of a coherent personal story (Sitvast & Abma, 2012, p.178). Furthermore, meaning making from forming illness narrative demonstrates

how patients *'struggle for authorship of their lives'* and in finding resolution, patients can portray increased 'sense of self-efficacy' (Sitvast & Abma, 2012, p.178).

Linearity (describing a consistent straight line) is a concept linked to trajectories of life which are normally uninterrupted (Lakoff & Johnson, 1980). Ricoeur (1984, p.65) said that a simple list of events in chronological order is not enough to create a story:

> *'a story, too, must be more than just an enumeration of events in serial order, it must organise them into an intelligible whole of a sort such as we can always ask what is the thought of this story.""*

This suggests that an ability to provide clarification of the narrative in the diary is incumbent in the process of its provision. The story of the missing time needs to be chronological for participants and they expressed concern when dates were omitted from their diary. In forming the story participants need to be able to articulate what they have been told to aid in forming their own interpretation and so they begin to assimilate the story with the meaning behind it. The handover of a diary is not enough there needs to be opportunity to explore what it says.

Exploring existing theory led to exploration of the following work by Antonovsky and its applicability to the points highlighted so far in terms of diary use and recovery from illness.

8.6 Comprehensibility, manageability and meaningfulness

ICU survivorship has been highlighted as an increasing issue that leaves patients facing increasingly lengthy recovery, which now reflect chronic illness trajectories. Discharge from critical care can no longer be perceived as an end point for care provision; patients and their families require support in the aftermath of the critical illness recovery process (Rooney, 2013). Development of initiatives that are aimed at prevention or treatment of critical care related debility is warranted in light of the evidence (Iwashyna *et al.,* 2010, Rattray, 2013).

Through theoretical sampling the researcher found parallels between critical illness experiences and experiences in research on chronic illness. This led the researcher to Antonovsky's theory about patients need for a 'sense of coherence' regarding their illness and explained that lack of 'coherence' was a major source of stress and associated with reduced capacity to cope. He wrote about patients need for their internal and external environmental stimuli to remain structured and predictable; that patients require resources to cope with any changes to the equilibrium of these stimuli and that the patient feels that facing challenges to their normality are worth their effort to address. In this context Antonovsky (1979) outlined three components: comprehensibility, manageability and meaningfulness as explained below:

- *Comprehensibility*: a belief that things happen in an orderly and predictable fashion and a sense that you can understand events in your life and reasonably predict what will happen in the future.
- *Manageability*: a belief that you have the skills or ability, the support, the help, or the resources necessary to take care of things, and that things are manageable and within your control.

- *Meaningfulness*: a belief that things in life are interesting and a source of satisfaction, that things are really worth it and that there is good reason or purpose to care about what happens.

These three components demonstrated close fit to the components of the emergent grounded theory in the current study and were therefore explored further and incorporated in conceptual map figure11 p.251 and then delimited and reduced to highlight the key aspects included in the theory as shown in figure 12 p.304.

Antonovsky perceived meaningfulness as the most important component, stating that if a patient has no sense of meaning, then they will have no motivation to comprehend and manage events. He argues that 'salutogenesis' depends on experiencing a strong 'sense of coherence.' Salutogenesis is defined by the World Health Organisation (WHO) as:

> *"the process of enabling people to increase control over, and to improve their health and thereby enabling people to lead an active productive life towards wellbeing and quality of life".(Ottowa Charter for Health Promotion, 1986).*

The research by Antonovsky demonstrated that the sense of coherence predicts positive health outcomes. Relating this to critical care diary use seems to be a logical step. The critical care diary is ostensibly a resource that patients choose to access and engage with, or not, and it plays a role in comprehensibility of their critical illness The diary can provide acknowledgement of the life threatening nature of events that occurred and which participants struggle to comprehend, because of their perceived

amnesia about that time. It can facilitate participants' relationship to the critical illness events of which they feel they have played no part. The diary as a chronological overview is vitally important to this process and can have positive or negative impact depending on the ability of the diary as a resource to meet participants' needs during recovery.

Manageability seems to pertain to family or psychosocial support that participants had available to them and this support combined with critical care diary use can contribute to regaining control over events, by assimilation of the information sources available to them and the development of participants' own interpretation of the story of their critical illness.

Meaningfulness is about making sense of events that occurred, it relies on the use of the sources of information available to them in drawing together their illness story so that they no longer have a rift in their life story narrative that otherwise can leave them with uncertainty and anxiety. Salutogenesis could be argued as the stage where participants felt they had come to terms with what happened through finding coherence and feeling able to move on with their lives.

All the conceptual categories and associated coding from chapters 4-7 and theoretical sensitivity led to the emergence of the core category: needing coherence, which is crucial to the emergence of the grounded theory. The core category is

explained next followed by analysis of the literature leading to the development of the substantive grounded theory.

8.7 The core category: needing coherence

The core category that emerged is needing coherence. This consisted of participants continually striving to resolve the rift in their life story and their sense of self-identity. Furthermore, their uncertainty and need to know what happened was important in gaining coherence. Participants described a process of being ready to know what happened and sought from all sources available to them, including their diary, to construct their illness story and to form their own interpretation about what happened to them. Participants shared that because they could not remember their critical care admission they had problems comprehending what their illness entailed and they did not know what expectations to have of their health and recovery. All these aspects meant participants needed validation of how ill they had been so that they could make sense of it all and this gave them coherence over their recovery process.

The continuing resolving of this main concern is accounted for by participants' desire to fill in the void in their memory by assimilating information from family, HCPs and their diary: seeking coherence. They use the information to help them develop their own interpretation of what happened to them. Knowing what happened and feeling a connection to events from which they feel detached enables some participants to feel a sense of life story coherence that they had lost during their period of unconsciousness. Integrated within this is participants' reclaiming of sense of self-

identity. Participants explained it was difficult to understand what they had been through; to conceptualise and accept the reality of how life threateningly ill they had actually been. The diary has potential to give meaning to a significant episode of their lives, of which they felt they had no part. A note of caution is required as not all patients cope in the same way and whilst this process worked for most participants in the study, for others, like Emily and Harry, diary use was potentially counterproductive.

Participants sought validation or confirmation about how life threateningly ill they had been and in some cases they were still struggling to understand this at six months in to their recovery; describing the shock that they felt by the enormity of coming to terms and accepting it had happened to them. In most cases participants felt their critical care diary was an important piece of the jigsaw and acted as a potentially supportive resource in their recovery process. However the manner in which the study site administered the diary process was potentially not conducive to facilitating participants' health and wellbeing. Diary use in isolation from on-going support and opportunity to discuss content and their feelings made the process potentially a superficial, if not risky endeavour for participants.

Addressing their uncertainty or *"loss of control"* by knowing what happened were important in their needing and gaining coherence for most participants. By participants seeking sources of information available to them, most were able to construct their illness story and to form their own interpretation about what happened to them. This created a sense of closure for most participants, but for Emily it was a

source of further angst. The diary in isolation is therefore arguably not enough. As part of needing coherence participants sought validation or affirmation of how ill they had been. When it was able to do this diary use gave some participants control and confidence during their recovery process. When it failed to meet the participants' needs, as in Emily's case, it potentially hindered her ability to move on.

In terms of diary use, over time data showed that with the use of their diary, most participants were able to start to piece together information in conjunction with what family had shared with them. While others found it prompted more uncertainty and confusion about events that did not match what family told them. So the diary plays a key role in coherence or sustained incoherence about the events that occurred. Then there was no follow-up to identify any on-going concerns or to provide clarification.

Final interviews demonstrated that most participants had developed new knowledge and coherence about their critical illness episode and could recant these in the form of a newly formed story. This story did not need to be completely factual for the participants, but enough of a story to enable them to feel a connection to an episode in their life that they could previously not recall: coherence over their missing time. In some cases not knowing may be a better means of coping with traumatic events and proponents of diary use need to be mindful of this (Bonanno *et al*., 2011).

Needing coherence through knowing what happened emerged as a central component part of recovery for most participants, who felt it was necessary to repair

the rift that existed in their life story due to *"being out of it"* so they could find meaning behind the events that occurred and encompass information to form their own interpretation of their critical illness story that eventually becomes part of their memory system; despite their feeling of disconnection from events and this has been described in research on amnesia (Rosenbaum *et al.*, 2005).

8.8 Explanation of the grounded theory

A grounded theory of needing coherence: repairing the rift in life story and self-identity after critical illness and establishing the role of the critical care diary

The theory that emerged from analysis of the data in the current study is that humans seek coherence about what happened during their critical illness. It has been identified that participants being ready to know what happened is important in how they approach their recovery process. Those patients who feel ready to know need to replace the disruption or rift that has occurred in the normally intact timeline of their lives. In order to do this, patients draw on relevant information available to them. Having a critical care diary can be instrumental in helping patients resolve the uncertainty, anxiety and stress that negatively impacts on their health and recovery. However it can also fail to allay concerns and thus increase anxiety and rumination where questions are left unanswered.

The work by Antonovsky (1979) on sense of coherence is important in the emergence of the substantive theory. Table 14 below outlines some important relationships between Antonovsky's theory and the current study:

Table 14: Antonovsky's work combined with conceptual categories and associated codes from the current study- outlining the role of the diary

Role the diary can play: Coherence		
Comprehensibility	Manageability	Meaningfulness
Chronological	Answers & insight	Understanding & beliefs
"Being out of it"; "lost days" and "memory loss"	Recovery: "Is it normal to feel like this?"	"Something I must know"
Regain control Confidence	Reality of illness Dates	Being ready to know Realistic about critical illness events & implications for recovery. Make sense & come to terms Self-identity
Recovery is facilitated with reduced risk of psychological problems and an acceptance of physical limitations		
When the diary is incomplete or does not say enough: Incoherence		
Loss of control and confidence persists	Overwhelmed with unanswered questions & uncertainty with anxiety	Remain in a state of flux about what happened to them
Increased risk of psychological problems and reduced physical recovery		

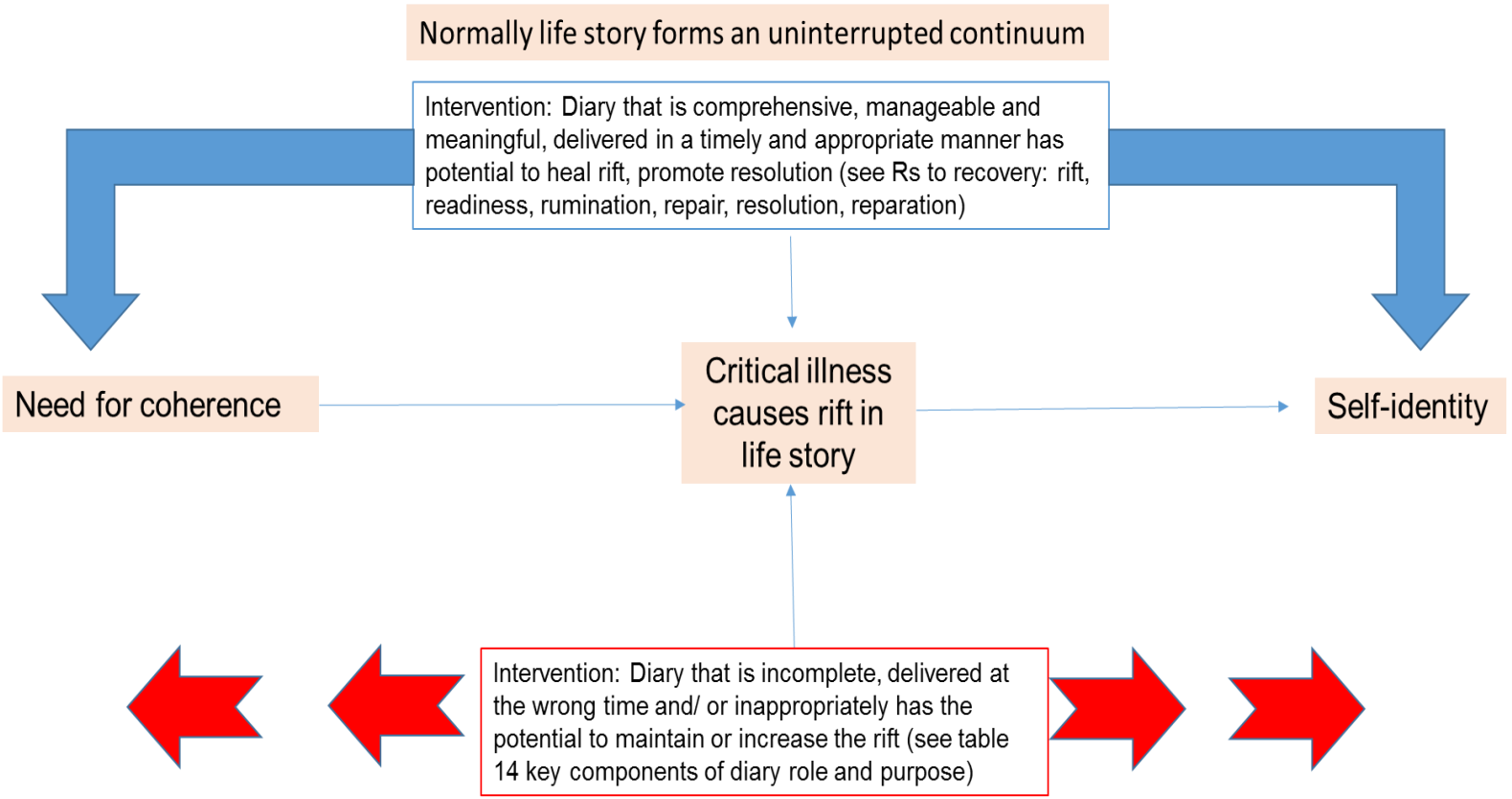
The diary provided for the patient to read needs to be comprehensive, meaning that it covers the chronological timeline of their illness and that content provides explanation that patients can understand about any key events, moments or discussions held between family and HCPs. Therefore this information needs to be manageable in that it does not set out to overwhelm the reader and that there is a sensible commentary to follow. The diary should be meaningful to the patient for whom it was written and that entails consideration of points summarised in table 14

above. Coherence underlies these processes of comprehensibility, manageability and meaningfulness described here and are important to the substantive theory.

The terms chronology, answers and insight, understanding and beliefs emerged during analysis in the current chapter and have been used in the table above to demonstrate how the conceptual categories fit beneath them. Underneath the conceptual categories are key issues that arose in chapters 4-7. Even though chapter 7 is not assigned a column its implications are integrated in the table above. Distinction has been made about the role the diary plays when it works or fails to capture the information required.

Participants can regain their sense of self-identity through understanding and accepting the reality of their critical illness journey. Equally if the diary fails to meet patient expectation incoherence can remain with clarification of what happened filing to be achieved Figure 12 p.304 below outlines the delimited and reduced substantive theory.

Figure 12: The substantive grounded theory of needing coherence: repairing the rift in life story and self-identity after critical illness and establishing the role of a critical care diary.



The substantive theory is needing coherence: repairing the rift in life story and self-identity after critical illness and establishing the role of a critical care diary.

Figure 12 p.304 demonstrates how critical illness influences patients concept of their lives: coherence and who they are: self-identity. Life story is usually perceived as an uninterrupted continuum. In critical illness there is a rift that occurs in perception of life story. There are two aspects that influence the usefulness of a critical care diary. The first being: comprehensive, manageable and meaningful diary provision has the potential to heal the rift in life story and to promote resolution. The second is that a diary that is incomplete and /or delivered at the wrong time or inappropriately has potential to maintain or increase the rift in the patient's life story. Both diary interventions will have an impact on patients need for coherence and their self-identity during recovery.

Theoretical analysis lead to the development of Needing coherence: The Rs to recovery after critical illness. This represents seven key elements described by participant (these are not sequential, rather they interlink and overlap): rift in life, readiness: being ready to know what happened, rumination which is linked to anxiety and depression, repair voids; where the critical illness story is created from the resources available, resolution where participants needed to know to make sense of what happened to resolve the situation, reparation: where participants sought to repair what had occurred through the construction of their own interpretation of their life story and regain their self-identity. Recovery was influenced by all of these factors and the diary content directly impacted on the process. The diary needs to be comprehensive, manageable and meaningful to the recipient.

In order to be comprehensive, the critical care diary needs inclusion of all the dates and key events or changes in a chronological manner. It would be beneficial if a lay summary could be included, which could also form the discharge letter to the GP. Ensuring the critical care diary is manageable relates to how it is constructed, the manner in which it is written and the authenticity of the content. This will be affected by the author's honesty or the way in which they choose to censor entries. Participants in the current study wanted enough detail to appreciate how ill they had actually been, including some recognition of difficult conversations held between HCPs and family. The actual commitment of nurses, other HCPs and family and friends to contributing to the diary and writing in a personal manner made the diary a more meaningful resource for patients. The diary had potential to reflect a caring relationship that was unable to be established between critical care staff and the patient whilst unconscious.

The diary could provide a source of reassurance when done well, but not if the patient felt it was too brief or superficial. An important aspect of having a critical care diary is its ability to validate how ill the patient has actually been and to alleviate their uncertainty. Part of needing coherence relied on affirmation and the perception of permission to feel the way they felt during their recovery.

These processes described above can facilitate a diary that helps patients feel a sense of control over their life. Needing coherence is a fundamental aspect to understanding why their physical and psychological health takes a long time to improve; or accepting that they are left with limitations. In seeking and gaining coherence the insight offered by their diary has potential to facilitate a manageable

recovery process by helping participants accept and come to terms with events and move onwards with their lives. Ultimately participants wanted enough information to build a comprehensive story of their missing timeline. However, equally a diary that is incomplete or inappropriately shared with a patient has potential to maintain or exacerbate the lack of coherence patients feel. Thus a diary could help or hinder recovery; having potential to be either beneficial or harmful to patients recovery.

Table 15 below outlines the role and purpose of diary writing as elicited from participant data in the current study, specifically data analysis from chapter 7 in addition to some key points highlighted from analysis included in chapter 8. This could be used as terms of reference for clinical practice when developing, implementing and applying diary use.

In order to use the theory a few aspects from the thesis would need to be available to HCPs to aid in improving diary use in critical care: table 12 p.269 would be handed out in conjunction with the substantive grounded theory figure 12 p.304 and key components of the diary role and purpose table 15 p. 308).

Table 15: Key components of the diary role and purpose in the current study

REASSURANCE, REPRESENT RELATIONSHIP AND TRUST	The way the diary is written matters. By using a personal approach it can demonstrate that they were cared for and treated as a human being. HCPs taking the time to write in the diary is valued by patients as showing commitment to their well-being and allows formation of a trusting nurse-patient relationship that was missing while the patient was unconscious.
CHRONOLOGICAL ACCOUNT OF MISSING TIME	There needs to be something written for each day, otherwise it can cause anxiety about what could not be said. The initial period of critical illness needs to be captured in some way, even if retrospectively as the initial few days may be the most life threatening and if this is not captured the mismatch between the diary and family portrayal can add to confusion.
CONFIRM OR VALIDATE ILLNESS	Being ready to know is an important part of the process for patients. The diary needs to contain enough depth of detail to help the patient piece together key events or discussions that were held. It almost needs to reflect the salient points from the shift handovers. The diary plays an important role in validating or confirming how ill the patient actually was. Provision of a photograph or by reading their diary they can gain acknowledgement and permission to feel the way they do during their recovery
MEANINGFUL CONTENT	The content of the diary is there to help the patient (in retrospect) feel part of something that happened to them. When writing entries the HCP needs to be mindful that the content will be used to form threads of the patients missing life story for that period of time so they can rebuild the coherence that they normally hold over their life.
LIFE STORY AND COHERENCE	The disruption to the normally intact notion of their life caused by critical illness is significant. Missing time is a vulnerability and a sense of loss of control is inevitable. Capturing enough detail to help form their own interpretation of events is important for peace of mind and moving forwards with recovery.
SELF-IDENTITY	The rebuilding of the missing storyline is important to the patients' sense of identity and well-being.

8.8.1 Reflexivity

As a novice researcher it was difficult to manage the huge amount of data produced during interviews and the overlapping processes (interviews, transcribing, analysing, memoing) involved in constant comparative analysis. There were times when information was overwhelming and I had to prevent myself from allowing my own preconceptions as a critical care nurse from influencing the research. I used the strategy of making frequent memos, and reflexivity within them, about my research to help me maintaining the integrity of what participants said rather than on the thought processes that I may have encountered in response to data and my clinical background. Using written and recorded memos I was able to think things through more clearly and identify when I was going off on a tangent.

Being a critical care nurse meant that I found everything that participants shared fascinating. In hindsight I can see that this hindered my ability to narrow in and focus on diary use without the critical care context of their experiences. I would like to think I am now enabled with the knowledge and understanding of myself as a researcher and the influences that can impair the process so that I can strengthen future work that I may do.

The impact of critical illness is diverse and becoming more long term for patients. I have found the research study and reading the literature inspiring. The most impact on me as a person and researcher though has been through meeting the participants and them sharing their experiences with me. I found their experiences fascinating

and felt the context was important. However in hindsight I would be more confident in using the interview guide at the outset to maintain a clear focus on the study aim and questions. I recognise now how my own uncertainty meant I probably created a lot more data than was necessary for the study.

My influence on the theory that emerged has occurred because of my incorporation of the participant stories in the interview phase rather than adherence to diary use and role as per the interview guide. If I had not established the background detail and maintained focus from the interview schedule I think the theory would still have arisen, but I could have saved myself a lot of transcribing and data analysis with a slick approach. It has made me more appreciative of the preparation process required before starting data collection. Recruitment failed to establish an equal representation of men and women and I could have changed tactics to facilitate this. I did not stick to my original interview guide, which meant my control of the information participants shared was too loose and this has impeded the process.

My personal growth and development as a researcher during this study has been very important to my future research career and my lecturer role.

8.9 Summary of chapter

The substantive theory is that humans seek coherence about what happened during their critical illness. Part of the process encompasses patients being ready to know

what happened. Those patients who feel ready to know need to replace the disruption or rift that has occurred in the normally intact timeline of their lives. In order to do this, patients draw on relevant information available to them. Having a critical care diary can be instrumental in helping patients resolve the uncertainty, anxiety and stress that negatively impacts on their health and recovery. However it can also fail to allay concerns and thus increase anxiety and rumination where questions are left unanswered; acting as a potential hindrance to recovery.

Needing coherence incorporated resolving the rift that had occurred in their life story and thus their concept of self-identity during the missing time. Recovery was also about addressing the uncertainty that participants were left with and the impact this had on their sense of control over their critical illness. In order to find coherence participants needed to be ready to know and then to find out what happened: needing coherence. This process required them to draw on sources of information available to them, such as their diary, family and HCPs, to help participants construct their illness story in a manner that works for them. It has been established that a dairy can potentially help or hinder this process.

The grounded theory needing coherence: repairing the rift in life story and self-identity after critical illness and establishing the role of the critical care diary has been explained using a conceptual map (Figure11, p.251). The conceptual map outlines the key factors that play a contributory role to the theory. There were many aspects to consider and these were delimited and reduced to provide the substantive grounded theory (figure12, p.304). Figure 12 is able to be used in clinical practice to

help HCPs understand the implications and rationale for implementation of, and administration of the diary through their written entries. In conjunction with table 15 p.308 HCPs can use the information to help them determine the usefulness, or not, of the diary for the patient when they read it seeking coherence of their critical illness journey.

Chapter 9: Conclusions and recommendations

9.0 Overview of the chapter

The final chapter considers the overall study, starting with the aim, objectives and findings, followed by evaluation of the limitations and strengths. Conclusions will be drawn. The original contribution to knowledge will be presented, followed by implications and recommendations for clinical practice, education and future research.

9.1 Reflection on the original intent of the study

The aim of this study was to provide in-depth insight into critical care survivor experiences and use (or not) of a critical care diary during the first twelve months of their recovery to inform development of theory and future diary use.

The following objectives of the current study are listed and then explored in order below.

To critically explore participants':

1. Experiences of critical illness and their ensuing recovery during the first 12 months.
2. Use of their critical care diary (or not) including if, when, and how they used it and to elicit how diaries may be useful at different time points during their recovery and rehabilitation.

3. Perceptions of diary content (type, breadth and depth), impact of this and role, if any, they felt their diary had for them during their recovery.
4. Environmental and demographic factors that may impact on perceptions of the diary

1. Experiences of critical care and the ensuing recovery period.

There is a lack of longitudinal research in the current literature related to critical care diaries. The decision to use a twelve month period of data collection for the study was important because in a year it is feasible to capture the main aspects that impact on critical care survivors and their recovery. For example at two months some had not been to collect their diary, at six months all who wanted their diary had collected it and all had hurdles to overcome regarding their physical and psychological limitations following their illness. At twelve months participants were dealing with the anniversary of events and psychological symptoms manifested in some cases.

Experiences of critical care and ensuing recovery period were shared by participants and findings have been explored in chapters 4 to 7. They have been further analysed as part of the emergent theory in chapter 8.

The current study adds to the body of knowledge about patient experiences of critical illness. Findings demonstrated the main issues participants experienced in terms of critical care. These were *"being out of it",* which encapsulated the significance of having been sedated and ventilated, thus left with no, or distorted memory of their

time in critical care. In conclusion it seems that a period of unconsciousness is initially more perturbing for participants than the fact that they have been critically ill. The process of connecting of information about what has happened to them during the *"lost days"* is pivotal to their ability to gain a sense of coherence about their critical illness journey and to alleviate their anxiety.

Recovery was impeded by a lack of understanding by participants about what had happened to them, the reality of their critical illness events and care required. They said they did not know what was normal to expect after critical illness. It took time for participants to come to terms with, and accept the reality of how ill they had been. There was an active process of seeking validation or confirmation and almost a needing of permission to feel the way that they did. Their recovery was not as quick or as full as they initially thought it would be. Participants acknowledged limitations physically and psychologically that they had difficulty in comprehending.

There was a need to know what had happened and to gain a sense of coherence about their illness events and implications on their health and well-being during recovery from critical illness. Their family played a role in providing some context, but they were not always open and honest with their loved one. Perhaps preferring not to relive what they had witnessed. Participants felt abandoned on discharge by the health service after their life threatening illness. They all felt further support and explanation should be provided during recovery from critical illness.

2. Use of their critical care diary (or not) including if, when, and how they used it and to elicit how diaries may be useful at different time points during their recovery and rehabilitation.

Participants used their diary as a resource for information that they could not remember about their time in critical care. In some cases their diary was incomplete or did not provide the information in sufficient depth for them to find it useful. The diary was read immediately they had it and in the study site no sit down handover was conducted. There was no provision of support thereafter. However participants wanted some form of follow-up to acknowledge how ill they had been and to provide opportunity for clarification and answering of questions. They used their diary when they had friends or family visiting as a way of sharing and discussing what happened. They also returned to it when they had doctor's appointments or if they had a bad day. They needed it as the anniversary of the critical illness event approached. It was useful in helping them to understand, come to terms, accept and move on from what happened.

3. Perceptions of diary content (type, breadth and depth), impact of this and role, if any, they felt their diary had for them during their recovery.

The study findings identified what participants thought of their diary (type, depth and breadth of content), contributing further insight into what is already known. It demonstrates the importance of a chronological, day by day account. The commencement of the diary needs careful consideration. Omissions and missing dates led to further anxiety and concern for participants.

So the comprehensibility, manageability and meaningfulness of the diary in terms of reaching what Antonovsky (1979) would call salutogenesis is potentially an important role of the diary to participants. Salutogenesis comes from the Latin *salus* meaning health and Greek *genesis* meaning origin. This term was coined by Antonovsky in trying to explain how individuals' deal with stress and maintain health. He wrote about the way individuals use resources as a means of finding sense of coherence. He posited that stress causes harm when it goes beyond that of every day stress to a point where it 'violates' the individuals' sense of coherence. This occurs because the normal predictability of daily life is disrupted in some way and the resources available to address this instability are lacking. Finally the individuals' self- belief is compromised and they struggle to overcome and recover from their illness. This highlights the role a critical care diary can play as a resource for critical care survivors in overcoming their apprehensions. Equally though it has to be considered that exposing a patient to a diary is fraught with issues around when, how and where to do it. The potential of the diary to help or hinder patients' recovery cannot be ignored. Therefore it is a process that needs to be carefully considered with supportive mechanisms in place to suit a variety of patients' needs.

In some cases the diary validated or confirmed how ill participants had been, but not if content was too brief. It allowed participants to reconcile what had happened and regain self-identity for the missing time. The diary provided a chronological story about the missing time that they trusted more than what they family told them. Diary content could demonstrate that they were cared for by the nurses and treated humanely as a person. Unless a key nurse did not contribute, then they were left wondering. Diary content could include family entries and reflect normality, such as

weather, who visited, how family felt and encouragement from family to get well. Having the diary could provide peace of mind and comfort about the missing time. Inclusion of a photograph was deemed important by participants as they wanted it to facilitate visualisation of the reality of how they looked whilst critically ill. Having a diary may be construed as too confrontational and introducing the patient to memories that they did not have could be traumatic and lead to psychological complications that previously did not exist or are now further exacerbated.

Providing a diary like an afterthought needs to be avoided, if protecting critical care survivor psychological well-being is the goal. It has emphasised the potential benefit versus harm concern and demonstrated that diary use in isolation needs to be avoided in favour of provision of a diary with follow-up. Opportunities to improve communication (information, explanation and clarification) need to be explored in order to enhance future service delivery and ultimately patient recovery and progress.

The type of diary participants wanted needed to be personal, open and honest, within reason. They wanted their diary to capture as much information as possible with enough detail to help them understand the severity of their illness and what discussions were held. Often family told them about the moment they were told their loved one may not survive, but this sort of information was not always included in the daily updates in the diary.

The impact of the diary was that when done well, it could validate or confirm how ill they had been. This could provide elements that they could assimilate to help form their own story of the missing time. During recovery they used the diary as a point of reference or as an aid memoire. It could clarify information, prompt discussion and when done well, they could use it for others to read so they too could understand how ill they had been. Some continued to add photographs and other information to their diary. Their diary was important to them and just knowing it was there was important. It had potential to provide a source of comfort and peace of mind. The personal way in which it was written to them by nurses and other HCPs provided reassurance that they were cared for.

The role the diary played was important in removing uncertainty, anxiety and stress. The diary played an important part in restoring a sense of control by providing coherence that was missing from the concept of their lives. However, when the diary was incomplete or stopped too soon it could be counter-productive to their health and well-being.

4. Environmental and demographic factors that may impact on perceptions of the diary

A demographic sheet for collection of key information regarding participants was devised and discussed with the diary team. However completion of the forms was not achieved consistently. The interview process was intense with constant comparative analysis meaning overlapping interviews, transcription and data analysis and as part of this process the researcher was able to derive enough

information to produce an overview of the demographic factors (See chapter 3, table 4, p.72). Analysis of environmental factors was not pursued in the current study.

9.2 Conclusions

Patients' perceptions of having a diary kept on their behalf is lacking in existing research. The current study identified that most participants wanted to know what happened to them, but some did not and rationale for this has been identified as due to differences in coping strategies.

The study site did not offer opportunity to discuss the diary or to talk through key elements before it was handed over. The pattern of diary handover was to invite participants to collect their diary from critical care which was an emotional and difficult step for them. Then they were offered the opportunity to look around the critical care unit. It has to be noted that this process was usually occurring at six weeks post-ICU discharge home. The diary was then handed over as the participant left. This process seems to be a large burden for patients' who have just survived a potentially life threatening illness and could put some off wanting to collect their diary.

Those participants who did want their diary hoped it would help them gain coherence about their period of critical illness. Most participants had no memory of events and found the rift or disruption to their life timeline troublesome. Not being able to comprehend the reality of how ill they had been meant participants struggled to know

how they should feel during their recovery. Participants who wanted their diary read it immediately they got home. The study site at the time offered no follow-up or support group for critical care survivors and their family.

The timeline and key events need to be captured. Missing dates in their diary caused concern for participants and they wondered what was so bad that nothing was written for that day. The study site did not commence the diary until 48 hours after admission. This meant the pivotal life threatening stage of illness could be omitted from the story being provided in the diary.

Reading a diary about what has happened can be an opportunity for patients to comprehend what occurred and it can be seen as an independent record of information that corresponds with what family said; or it may omit or contradict it. In this case participants who found their diary lacked the detail they expected or required, like Emily, actually were left ruminating with more questions and potential anxiety as a result.

It raises the point that a retrospective element might be required in the diary to ensure it captures the main events and decisions for the patient to read during recovery. A lay summary or discharge summary that can be added to the diary as well as used to inform the GP has potential for use in this context. It could also offer an alternative to diary provision. Participants valued their diary and the personal nature of it. In some ways the diary was a means of connecting with the nurses who

cared for them and being reassured that they were treated as a human being while unconscious and vulnerable.

Implementation of a diary places onus on HCPs to ensure that there is a facilitated support system in place. A diary used in isolation as described in the current study risks exposing participants to confrontational or emotive information and then expecting them to use it like a self-help tool. This would require resilience to do so at a time when the patient may not have those reserves.

A diary as a resource to aid in debriefing post critical illness and during recovery is one thing. Even using it as a debriefing tool is contentious because one off debriefing has been found to have potentially detrimental effects on patients' who have been through traumatic events. Diary use may not be purely beneficial; potential to cause harm is evident from participant experiences shared during the current study. Aspects that raise potential concern are their use in isolation from continued support. Diary teams with no counselling training and no clinical psychologist input if a patient were to require it. Then the fact that there is no follow-up to identify any continuing concerns about the patients wellbeing. The integrity of the diary being handed over is important. It needs to capture the key events and provide a coherent, chronological timeline as the role the diary ultimately plays is in offering coherence about what happened during a period of time patients' cannot recall. It is also important that patients are able to accept or reject the option to collect their diary, as a coping mechanism for some patients may be not knowing what happened. It is important to

respect that individuals differ and one tactic that is seen as supportive for some may be detrimental for others.

Provision of a critical care diary is one means of trying to improve the psychological health and wellbeing of critical care survivors. This thesis has identified some of the challenges faced by participants in the current study. The in depth insight into perceptions of diary use, or not, during a year of participants recovery from critical illness contributes to existing knowledge and understanding. Learning from the current study the main conclusions have to be that any intervention aimed at improving patient outcome during recovery needs to be carefully considered. The purpose and role of the intervention needs to be clear and HCPs need to be consistent in its formation if it is to be fit for purpose for the patient for whom it was intended. Through the interview process and meeting participants it is possible the researcher played an important role in the existing gap in the provision and support of the diary. Therefore the researcher potentially became part of the intervention.

What participants' experiences demonstrate is a lack of awareness by the HCPs and supportive services about what individual patients needs are following critical illness and appropriate supportive measures are not consistently assessed and provided according to a needs based process. Clearly continuity of care between hospital, discharge and home could be improved. In two cases participants were referred to rehabilitation hospitals for on-going care before discharge home.

Needing coherence after a life threatening event which you cannot remember seems logical. However not forcing people to confront a situation for which they may not yet be ready is an important consideration.

Literature supports participants' experiences and ICU survivorship is seen as a major growing challenge for healthcare. Similarly to the literature on psychological needs and delayed service developments; ICU survivorship is slow to be acknowledged and addressed. Time, resources, and HCPs motivation and support to innovate clinical practice with patient centred initiatives is a challenge. The NHS is overstretched and basics of care are often the main concerns for the struggling system. While patient's needs and aftercare are given a lower priority; they remain vitally important to the chain of care. Acknowledgment of the severity of illness, the physical and psychological impact of critical illness and struggle for recovery through some form of follow-up support is something participants in the current study greatly needed. This is despite some literature suggesting follow-up is not useful. There appears to be a problem in health care provision currently in that HCPs are taking a step back from the patient once they are discharged from hospital; but this does not make it right.

9.3 Evaluation of the study

The current study was warranted in light of the lack of research based evidence to support critical care diary use. Using GGT held challenges as a novice researcher, but the end result has presented in-depth insight into participants' critical illness

journeys and use of a diary during their recovery. The use of grounded theory methodology has facilitated discovery of a substantive grounded theory of needing coherence: repairing the rift in life story and self-identity after critical illness.

The current study demonstrates that critical illness has a significant impact on patients' health and well-being. This results in uncertainty, anxiety and stress. Coherence of their critical illness episode and their interpretation of what happened is important in their comprehension of their life story and their self-identity.

The chronic nature of critical care survivorship is an increasing and on-going concern. Like cancer survivors there needs to be investment in developing recovery packages that provide the on-going information and support patients rightly expect.

9.3.1 Application of criteria for assessing quality of grounded theory in this study

The GGT methodology processes have been followed, unless stated otherwise. Adherence to the crucial stages of data analysis, development of coding to categories and the core concept have been demonstrated in this thesis through emergence of the substantive grounded theory as presented in chapter 8.

In terms of an audit trail every stage of progression of the current study has been kept in printed and bound versions as well as electronically. All study materials are

anonymous and safely stored. Trustworthiness of the data was maintained by the researchers' ability to track her steps throughout the various stages of the GGT methodological process in order to demonstrate findings were based on a rigorous analytical process and are original.

9.4 Limitations and strengths

9.4.1 Methodological challenges

In Glaser's view strict adherence to GGT has not been maintained in the current study. In terms of data collection, he does not advocate use of audio-taping and transcribing, he sees this as a need for full data capture. He prefers the notion that a GGT researcher would use field notes to capture data on a conceptual level (Glaser 1978, 1998). This would be unrealistic as a novice researcher and in demonstrating development of the study to readers of the thesis.

Other Glaser concerns are use of audit trails to validate research results and using qualitative research criteria to judge the quality of grounded theory. He advocates the criteria of fit, work, relevance and modifiability to judge this in GGT (Glaser 1978, 1998). However as a novice researcher having no prior knowledge of using GGT it was necessary for the PhD work to be reviewed by others. Therefore interviews were recorded and transcribed verbatim. It was unrealistic as a novice researcher to try to rely on field notes or memory. Furthermore there are records of every step of the study, because of the need to demonstrate to those reading the thesis that the work is original.

9.4.2 Limitations

Limitations of the study recruitment process are that the researcher failed to capture those who did not want their diary. The study information pack might not be the best way to recruit as participants may not want to engage in that way. A personal approach may have been more helpful in recruitment. So in hindsight the researcher should have considered meeting patient's face to face post-ICU transfer to the ward. The study could have been discussed and questions answered and it is possible that through explanation, and meeting the researcher, people who did not want their diary may have agreed to take part in the study.

This could have facilitated a balance of views that was one of the original study objectives and enabled further comparisons and analysis to have been made. Another consideration is that patients found the request to participate in the study too confrontational as the study information pack was sent out at six weeks, which is quite soon after their critical illness. Reading the study information was probably the last thing they were interested in doing. As the study was about patient diaries it is possible some patients ignored the information if they did not feel ready to face what had happened or knew that they did not want to collect their diary.

The sample consists of critical care survivors who wished to collect their diary. A limitation is that it does not represent those who did not want their diary, although it had been the intention to capture both perspectives. The sample was recruited from

one study site and therefore it cannot be assumed that it is representative and transferable to other critical care units using diaries.

Data saturation was also a limitation due to the time constraints of the study and that the recruitment strategy could have been different with the benefit of hindsight. The researcher should have used a face to face approach and spoken to patients after transfer from critical care to a ward environment.

There was a gender imbalance in the sample with more women than men. Admission to critical care predominantly men and if the researcher does a similar study in the future she would ensure equal representation of men and women. The gender imbalance means men's perspectives are not adequately considered in the current study.

9.4.3 Strengths

This research offers a unique insight into participants' perspectives by capturing the initial twelve month period of their recovery. This qualitative longitudinal study is an important addition to the body of knowledge on the topic of diary use in critical care survivors.

Using GGT as the methodology meant that participants' data were allowed to speak for itself. The study is representative of their experiences, which is currently missing

in the literature. Using GGT was an effective approach to discover new theory in relation to the study research questions, aims and objectives.

The grounded theory of needing coherence: repairing the rift in life story and self-identity after critical illness provides new insight into the impact of critical illness. The gap this creates in memory and disruption or rift in life story coherence and self-identity in relation to the missing time is significant. The critical care diary is potentially an important intervention that can enable the patient to come to terms with what happened to them and accept their critical illness. In this study data was collected on three occasions over a year and analysed at many levels, which aids in providing meaningful results. Without using a longitudinal approach it would not be possible to capture patients' interaction and engagement with their diary during the recovery phase. Also changes over time in participant perceptions about their health, well-being and concept of their life following critical illness would not have been able to be identified through an isolated interview.

9.5 Application of the theory in clinical practice

Critical illness often requires a period of induced unconsciousness *("being out of it")* and this is associated with patients experiencing missing time from their lives. Patients described being ready to know, then when ready a need to know what happened to them and question why they feel the way they do during recovery. A critical care diary can be a vehicle through which patients can gain insight into their missing time and what happened to them in critical care. It can provide clarification

and a regaining of control over their life if they can use it to facilitate formation of a coherent, meaningful and comprehensive story that they can assimilate to repair the rift critical illness left in their life story continuum.

The emergent theory regarding needing coherence provides a clear point of reference for HCPs who are involved in diary implementation and administration. Figure 11 p. 251 provides an overview of the salient points of the theory that HCPs can apply as part of education and training.

9.6 Researcher reflexivity

Reflexivity especially in relation to qualitative research enables the researcher to demonstrate trustworthiness of their findings. Reflexive means ‘to bend back upon oneself’ and in research it is described as thoughtful, self-aware analysis of the relationship between researcher and the study. It requires critical self-reflection of social background, assumptions, positioning and behaviour and impact these have on the research process (Finlay & Gough, 2003).

Critical care diaries were a new concept to me but I was interested in the psychological needs of critical care survivors. I have a critical care nursing background, but I had limited comprehension of the reality of the impact of critical illness for patients and their family. The study has developed my insight and appreciation of what participants went through and enhanced my nursing perspectives and therefore my ability to share this knowledge and understanding in

my lectures and tutorials. I was a novice at different points in my research journey. The first interview I did made me reflect on my approach and so I changed tactics, but in hindsight I should have had confidence in adhering to my interview guide as the data I collected did veer into critical care experience with me then exploring perceptions of the diary. In that respect I made the diary secondary and I had to remove my assumptions about critical care experience in favour of exploring diary use.

In hindsight despite the research indicating there was potential benefit and harm related to diary use I did find myself writing like a proponent for diary use rather than presenting an unbiased critical view of the findings. I lacked confidence throughout the research process because it was new to me and I felt vulnerable which reduced my self-belief. This did prove to be counter-productive in my research journey. However, I have come out at the end of the study with a more open mind, less need to feel I have to control things and freedom to grow. Having presented my work with a critical review representing the balance of benefit versus harm at conference and via TwitterChat I have felt empowered and notice my confidence and self-belief are growing again. I feel that humility can be a good thing, but in research you do have to overcome that.

9.7 Overview of the contribution to knowledge and understanding, and originality

The original contribution to knowledge made by the current study is the longitudinal approach that was lacking in previous research on the topic and provision of in-depth

insight into critical care survivors' experiences of critical illness, recovery and use, or not, of their diary during this process. The resulting theory is needing coherence: repairing the rift in life story and self-identity after critical illness and establishing the role of a critical care diary. The study has provided new insight into the role and purpose of a diary for critical care survivors, which contributes to the body of knowledge on the topic.

There are two aspects that influence the usefulness of a critical care diary. These being: comprehensive diary provision, where all dates contain a coherent overview of events; versus a diary that's content fails to meet patient need, such as due to being too brief or superficial. The diary that is handed over makes the difference between providing coherence or increasing incoherence for critical care survivors. It is evident that a diary may require retrospective information before collection by the patient to ensure that it can serve its purpose in providing coherence.

Theoretical sampling and analysis lead to the development of Needing coherence: The Rs to recovery after critical illness. This represents seven key elements described by participants: rift in life, readiness: being ready to know what happened, rumination which is linked to anxiety and depression, repair voids; where the critical illness story is created from the resources available, resolution where participants needed to know to make sense of what happened to resolve the situation, reparation: where participants sought to repair what had occurred through the construction of their own interpretation of their life story and regain their self-identity. Recovery was influenced by all of these factors and the diary content directly

impacted on the process. The diary needs to be comprehensive, manageable and meaningful to the recipient.

Restoring a sense of coherence to life and self-identity is important in the aftermath of critical illness and the period of unconsciousness patients have experienced. Critical care diaries can have an important part to play in this process; which can be beneficial or harmful in some cases. Proponents of critical care diary use need to be mindful of the harm that can occur if a patient is exposed to information that they may be unprepared to read and especially if that process of information sharing is not supported appropriately.

The substantive theory is that humans seek coherence about what happened during their critical illness. Part of the process encompasses patients being ready to know what happened. Those patients who feel ready to know need to replace the disruption or rift that has occurred in the normally intact timeline of their lives. In order to do this, patients draw on relevant information available to them. Having a critical care diary can be instrumental in helping patients resolve the uncertainty, anxiety and stress that negatively impacts on their health and recovery. However it can also fail to allay concerns and thus increase anxiety and rumination where questions are left unanswered; acting as a potential hindrance to recovery.

9.8 Implications

The diary team have initiated the ICU Steps model to provide group support for patients and their family. Some of the study participants took up the invite to take part in this. Anecdotally it has evaluated really well by those attending it.

Currently a business plan has been submitted by the critical care unit for clinical psychologist input and negotiations are ongoing for provision of follow-up at a place that is neutral rather than expecting patients to return to critical care to collect their diary.

We have discussed the idea of providing a lay summary of events to compliment diaries even if a retrospective summary of events is provided.

There were gaps in their diary that were troublesome for participants and in light of discussions about this the diary team have emphasised the need for the critical care stay to be chronological and to have an entry for every date; even if it is a brief as there was no change today.

The lack of information provided during the critical illness journey, particularly after transfer to the ward and prior to discharge home to help participants prepare for the potential after effects of critical illness was important. Even prior to collecting the diary, participants wanted to know more, which suggests that ward transfer as well

as discharge information for critical care survivors needs adaptation to meet their needs. It is important to consider whether a neutral venue, such as an out-patient clinic would be a more appropriate starting point for meeting to handover the critical care diary and furthermore this could be done as part of a series of follow-up appointments to facilitate critical care survivor recovery physically and psychologically with referral pathways if indicated to access the multi-disciplinary team member best suited to address any on-going concerns. In light of the study findings we need to review the standard ICU Steps information booklet provided by the founders (Peskett & Gibb, 2009) & ensure it encompasses what participants' have indicated is needed. Based on the study findings we need to discuss and explore if patients and relatives need different information booklets. We need to work on development of best practice guidelines and pathways for optimising critical care survivor recovery as well as clarity on the critical care diary process and evolution as a result of participant perceptions and feedback in this study.

Service provision, such as follow-up and diary team investment needs to be negotiated, resourced, designed and agreed to optimise critical care survivors' experience, acknowledge the severity of illness and facilitate multidisciplinary referrals to aid recovery if appropriate. Consideration is required for patients who may not want a diary. An ABUHB diary team website could be developed and could include resources to improve communication, information and explanation for patients and relatives as well as key contact detail about on-going support, such as ICU Steps meetings. Potential for shared critical care diary use between Health Boards to maintain the coherence of the story for the patient for whom it is meant.

The role of photographs within the diary is perhaps more important than previously appreciated and work needs to be done to ensure that all patients are offered a photograph and receive it if they wish to include it in their diary. The method of taking and storing photographs needs careful consideration, taking into account that a patient may not want their diary or photograph.

A database needs to be developed to aid in easy access to diary tracking process, including invites and collection. This could prove useful for audit or evaluation as evidence for diary team development and follow-up.

The diary invite needs to include information for patients about what the diary process entails so that it can reduce anxiety or give them permission to reject their diary.

The diary as a source of the participants' critical care story or journey can therefore be incomplete for a few reasons: the patient was originally admitted to a ward prior to critical care, the diary did not commence for 48 hours, the nurse did not write an entry for the shift or the diary ended on transfer of the patient. In a rare occurrence that a patient has more than one admission to critical care their diary should perhaps be triggered to recommence.

If a diary is going to be used mechanisms need to be in place to offer the opportunity to sit down and go through the diary and then it is up to the patient whether they choose to talk it through or just take it home to read. Perhaps if they want to take it away then before they leave a follow-up appointment could be made within the next 2 weeks so that any questions that they have can be answered swiftly rather than linger and ruminate.

The need for the diary to provide a full chronological overview of the critical care patients' journey may require a retrospective aspect to the diary whereby the author incorporates a summary of events leading to and including the first 48 hours of the critical care admission. A summary of events covering the initial reason for admission to critical care and accounting for lost days is an important part of the patient diary. Or a critical care discharge summary could be used instead of a diary. (Bench *et al.,* 2012).

Diary contribution currently tends to be down to nurses and a strategy is needed to increase and widen HCPs contribution. The lead consultant intensivist of the study setting has started writing in diaries about conversations he has had with the patients' family.

There are new and creative ways evolving to help critical care survivors and remaining open to alternatives is important. All patients are individuals with different

ways of dealing with things so alternative options for providing support during recovery is important.

9.8.1 Recommendations for clinical practice, education and future research

The current study has highlighted a few areas for development in terms of clinical practice, education and future research and these are outlined below.

Clinical practice

1. That the study findings, theory and framework can be used to inform development of diary guidelines regarding implementation and purpose and thus to ensure as far as possible the diary is written to meet patient needs during their recovery. Inclusion of a lay summary of events to compliment diaries may be useful, even if this forms a retrospective summary. If patients are offered a photograph it should be available to them.

2. That a neutral venue, such as an out-patient clinic would be a more appropriate starting point for meeting to handover the critical care diary. Diary handover is facilitated as an opportunity for discussion and diary use in isolation is avoided in favour of some form of follow-up process for patients and their families.

3. That best practice guidelines for diary implementation and use are needed to provide a structured framework for diary use, consistency of approach and

standards. These should be developed by diary team and other HCPs in conjunction with patient involvement as they are the intended recipients of the diary. Consideration needs to be given to using patients' experiences to inform a pathway for optimising critical care survivor recovery. There is potential for critical care diary use to continue between Health Boards to maintain the coherence of the story for the patient for whom it is meant.

4. That a specific diary team website or section could be developed and could include resources to improve communication, information and explanation for patients and relatives as well as key contact details about on-going support. The website should be developed by the diary team, patients and their families with the purpose being to provide a supportive resource about critical illness that could complement critical care diary use. Potentially use of patient stories in written or video form could be integrated.

5. That diary entries made by other HCPs were not a common occurrence and integration of the multidisciplinary team approach needs to be captured. So at handover a more collaborative critical care diary approach is shared with the patient to ensure a more coherent representation of their time in critical care.

6. That some form of pre-reading information about critical care diaries and the process is indicated to accompany the invitation to collect the diary.

Education

7. That education and training of nurses and other HCPs is required on the experiences of critically ill patients and families. There needs to be greater

awareness of the impact of critical illness both physically and psychologically. Education and training should be provided as part of an induction for all new staff to critical care and pre and post-registration healthcare courses at the university.

8. That ward nurses and other HCPs should be provided opportunity to improve knowledge and understanding through exposure to critical care survivor stories and feedback to enable them to enhance their care provision in the aftermath of critical illness.

Future Research

9. That further longitudinal studies are conducted to explore patients' experiences of critical illness and to establish better insight into critical care diary use and its positive and negative ramifications. That research into a more diverse use of the diary, encouraging involvement of all members of the multidisciplinary team involved in the patients care, is warranted.

10. That research needs to explore the potential harmful effects associated with critical care diary use and identify how this can be identified and reduced or prevented.

11. That alternative means to provide critical care survivor support during recovery are explored in studies in a combined approach in provision of critical care diaries. An RCT could compare diary use versus diary use and follow-up, or counselling support.

12. That ICU survivorship is explored in the sense of long term impact on recovery to help identify ways of facilitating improved quality of life for critical care survivors.

9.8.2 Dissemination

The study has been presented during its development at local and national conferences. A poster about the study received second prize at the Chief Nursing Officer for Wales Conference. A short film was professionally made by StoryWorks using actors and anonymous participant quotations. The film was used to support an oral presentation at the British Association of Critical Care Nurses (BACCN) Conference. This film is now used as part of pre and post registration modules and in house training for the study site.

The current study was also presented at a Policy Forum for Wales Conference (2014) where it was heard by people in influential Government and Health Board roles. It is part of the research strand as an oral presentation at the BACCN Conference in September 2016. The researcher aims to disseminate the study findings at more national and hopefully international conferences. The study data and findings were presented as part of the Research Symposium at the British Association of Critical Care Nurses (BACCN) 2016 Conference. In January 2017 the researcher hosted a Patient Diary TwitterChat through BACCN and this prompted a lot of debate about the benefits and potential harmful effects of diary use. Discussion

included Peter Nydahl who is prominent in diary use and discussions and information was shared as far away as Chile.

The literature review was published in a peer reviewed journal, which does not have a high impact factor, but reaches a large number of nurses (Phillips, 2011). The researcher intends to publish papers in journals with a high impact factor, such as Critical Care (online publication, impact factor 4.476) and International Journal of Nursing Studies (impact factor 2.901, nursing journal with highest impact factor).

The researcher would like to submit proposals for research grants to enable further work to be carried out and develop a portfolio of research and expertise related to the current study.

9.9 Concluding statement

Aspiring to help patients' psychological well-being is a worthy position for nurses and other HCPs to hold. However providing a diary with lack of explanation or follow-up thereafter could have a detrimental impact. Therefore diary implementation requires strategic planning, education and preparation of those who wish to contribute. It also needs investment in follow-up provision.

The current study offers in-depth insight into patients' experiences following critical illness and sheds new light on the significance of a period of unconsciousness while sedated and ventilated for treatment in critical care. The role the diary plays for participants is dependent upon the type, breadth and depth of the content. When it works it has a multifaceted role in confirming or validating the reality of the severity of their critical illness. When it fails to provide enough detail it lost its value for participants and even became potentially counter-productive for their well-being during recovery. The substantive theory proposes that during recovery the diary can be a potent source of information, aiding communication about what happened and helping participants to develop their own interpretation of their critical illness journey and therefore a sense of coherence. A sense of control is regained helping participants to feel more confident about their recovery and future.

The substantive theory is that humans seek coherence about what happened during their critical illness. It has been identified that for patients being ready to know what happened is an important consideration for HCPs in the approach that is used in critical care diary processes. Those patients who feel ready to know, need to replace the disruption or rift that has occurred in the normally intact timeline of their lives and are potentially ready to collect and read their diary. Patients will draw on relevant information available to them, if this is offered or if there is opportunity for discussion. Having a critical care diary can be instrumental in helping patients resolve the uncertainty, anxiety and stress that negatively impacts on their health and recovery. However it can also fail to allay concerns and thus increase anxiety and rumination where questions are left unanswered; acting as a potential hindrance to recovery.

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Appendices

Appendix 1

PhD timeline

PhD chart (Original predictions)

	SEPT	OCT	NOV	DEC	JAN	FEB	MARCH	APRIL	MAY	JUNE	JULY	AUG	
2010-2011	ETHICAL APPROVAL LITERATURE REVIEW												
2011-2012	ESTABLISH INCLUSION/ EXCLUSION CRITERIA & RECRUITMENT PACKS & HEALTH PROFESSIONALS EDUCATION REGARDING THE STUDY & RECRUITMENT			**Recruit over 18 months**		Participant numbers (based on 14 as a guide)							
				1st interview at 2 months (60-90mins)		1 2	3 4	5 6	7 8	9 10	11 12	13 14	
				2nd interview at 6 months (30-60mins)								1 2	
				3rd interview at 12 months (30-60mins)									
				Data collection and constant comparative analysis									
2012-2013	Participant numbers (based on 14 as a guide)												
	3 4	5 6	7 8	9 10	11 12	13 14							
						1 2	3 4	5 6	7 8	9 10	11 12	13 14	
	Data collection and constant comparative analysis												
2013-2014	Complete data collection and final data analysis												
2014-2015	Complete thesis												

PhD chart (Reality)

	SEPT	OCT	NOV		DEC	JAN	FEB	MARCH	APRIL	MAY	JUNE	JULY	AUG	
2010-2011	ETHICAL APPROVAL LITERATURE REVIEW													
2011-2012	ESTABLISH INCLUSION/ EXCLUSION CRITERIA & RECRUITMENT PACKS & HEALTH PROFESSIONALS EDUCATION REGARDING THE STUDY & RECRUITMENT			**Recruit**	Participant numbers (									
				1st interview at 2 months (60-90mins)	1		2 3 4	5		6	7	8		
				2nd interview at 6 months (30-60mins)				1		2	3 4 5			
				3rd interview at 12 months (30-60mins)										
	Data collection and constant comparative analysis													
2012-2013		Participant numbers												
	6 7	8												
	1 2	3 4	5			6 7	8							
		Data collection and constant comparative analysis												
2013-2014		Complete data collection and final data analysis												
2014-2016		Complete thesis												

Appendix 2: Interview guide

Version 2 26/05/11

11/WA/0245

Interview Guide

Patient diaries in critical care: an exploration of patient perceptions

Interview themes at 2 months
Explore the participants' experience of critical care

Prompts
Why were you there?
What do you remember?
How did it make you feel?
What made you feel better or worse?
How do you feel your recovery has been?
Have your memories or views of critical care played a part in that or changed over time?
Were you aware of the diary?
Did anyone talk to you about it?
What do you think about it?

Interview themes at 6 months
Explore participants' perceptions of their recovery over the last 6 months and establish ongoing views of the diary.

Prompts

How would you describe your recovery over the last 6 months?
What has made it better or worse?
Did you decide to collect your diary or not? Why?
Is there anything that could have been done differently to facilitate your recovery process?

How have you found your diary?
(Further Prompts: At what stage did you read your diary for the first time? What have you done with your diary since you collected it? How often have you read it? How did you feel when you read it? Can you think of anything else that could have been done that could have been helpful?)

Interview themes at 12 months
Explore participants' perceptions of their recovery over the last 12 months and establish ongoing views of the diary.

Prompts
How would you describe your recovery since we last met?
What do you feel has affected that?
What would you say have been positive experiences?
What would you say have been negative experiences?
Did you decide to collect your diary or not? Why?
What do you think could have been done differently to improve your recovery process?

(Further Prompts: What have you done with your diary since we last met? How often have you read it? How does it make you feel when you read the diary? How significant was the diary for you?)

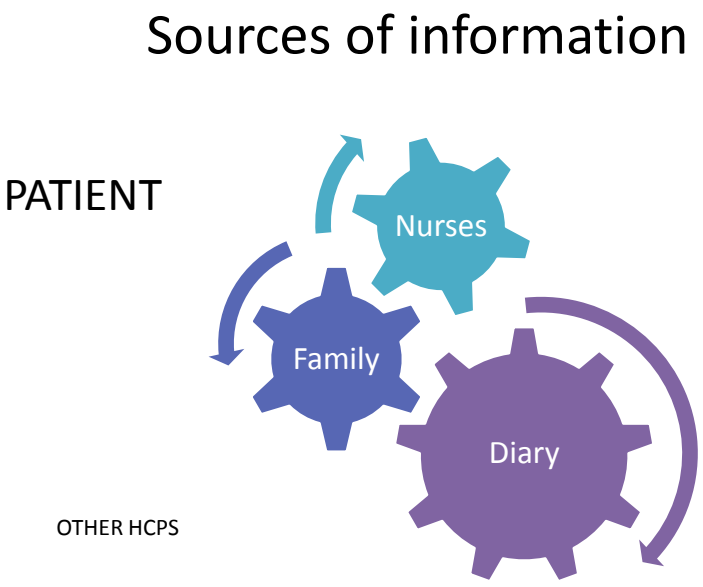
Appendix 3: Examples of thoughts and memos

Role of diary

- Resource- I can check that in the diary
- Validates- for some! tells me how ill I was and progress
- Reconciles- what happened, they existed on those dates.
- Story- covers the time they do not remember and diary goes beyond what their relatives tell them
- Care- covers nights when relatives weren't there
- Person- they call me by name. It's like they are talking to me.
- Normality- things were still happening while I was out of it.
- Comfort
- Peace of mind

Photographs

- Some were disappointed that there was no photograph
- It seems to form a visual record of their critical illness event
- It is evidence they did exist during that time they feel they have lost which aids in their quest for reconciliation of critical illness and memory loss.



Assumptions

- PATIENTS KNOW WHY THEY WERE ILL
- WHAT THIS ILLNESS WAS
- HOW IT WILL AFFECT THEM
- WHAT HAPPENS NOW
- HOW THEY MAY OR MAY NOT FEEL
- WHAT IS **NORMAL** IN THESE CIRCUMSTANCES

Reality

- SOMETIMES INFORMATION IS NOT PROVIDED QUICKLY ENOUGH
- OR IT CAN BE OMITTED
- WHEN SHOULD IT BE GIVEN?
- BY WHOM?
- IN WHAT WAY?

Role of the diary here is reconciling loss of memory and critical illness in conjunction with other pieces of the puzzle.

Does anyone actually tell them how they may feel and what might be normal for them?

- Would patients benefit from an information booklet outlining some of the key things related to critical care to take to the ward and home with them?
- Should someone or multiple HCPs with different roles sit down with the patient on the ward and explain their illness and answer questions?
- Let’s not assume this is done and perhaps this needs to be done on more than one occasion by various HCPs.

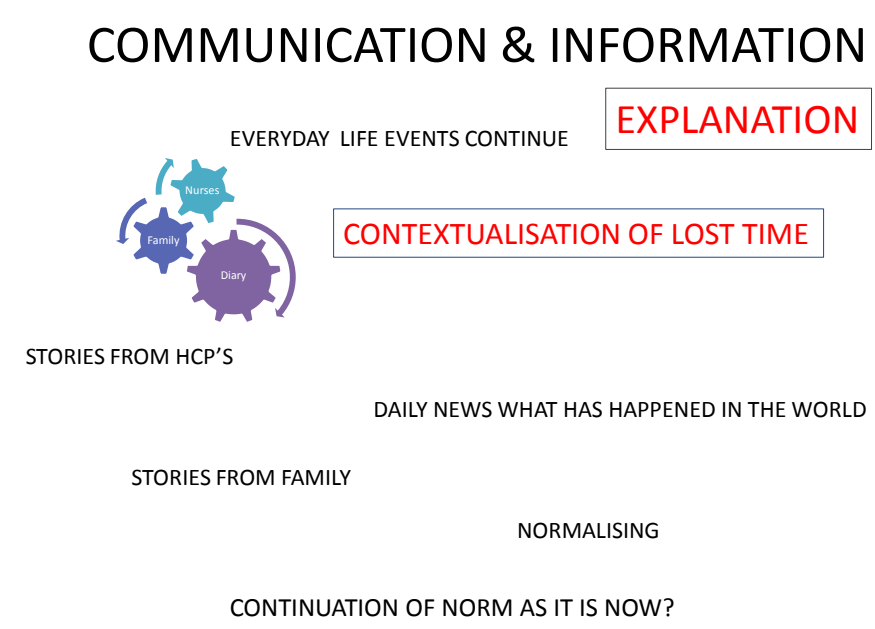
Diary

- can be incomplete- the notion of not starting the diary for 48 hours
- If that part cannot be done as a routine then perhaps an overview of key events and dates can be completed retrospectively as it appears to be a struggle to form the story of their illness instead of the memory that matters: their place in that time, existence, normality

- Perhaps use newspaper cuttings and include main headlines for each day. Part of quantification of occurrences so they can anchor themselves in the reality, time and space of the events that they cannot recall.

Participants

- NORMALISING
- RESILIENCE
- Relate to lost time via family, diary, nurses: assimilation of information for context
- Gaps in the diary raise concern as they can't relate to that time. (Worry that there is something that could not be said, were they cared for during that time? Why is it missing? Is my family telling me the truth?)
- Contextualisation
- Communication & information
- Continuation of norm
- Time, place, person relating to this through relatives stories about it and reading their diary written for them.



Communication & information & EXPLANATION & clarification

After critical illness how should they feel?

What may they experience?

Is that normal?

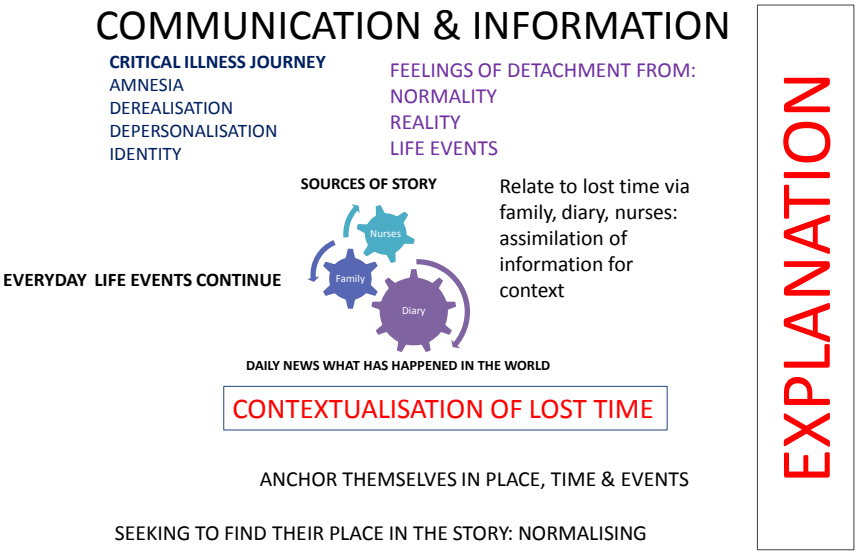
What is happening here in terms of diary team input?

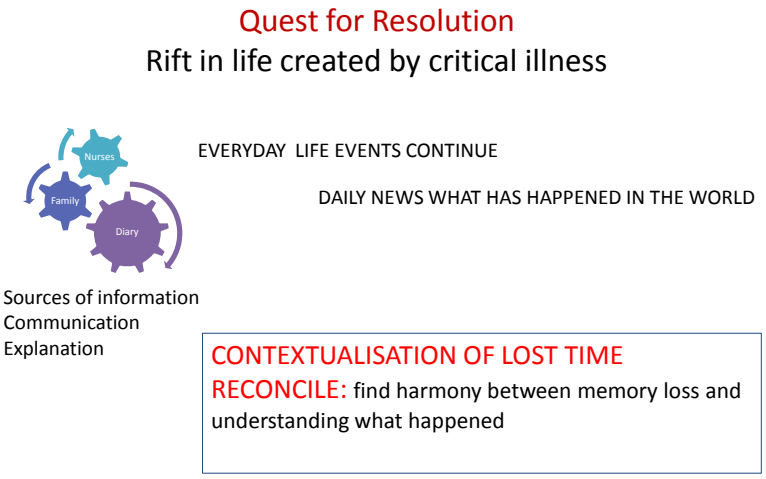
Expectation versus delivery

What role is the diary playing?

What is the main concern that keeps arising for the participants?

June 2012





July 2012

Construction, capture and coherence

Belonging and Ownership

Legal aspects of patient diaries

Paternalism and Censorship versus Authenticity and Transparency

Diary writing and constructing a story

Handover and Follow-up: support mechanisms and sustainability

Role of the diary, theories and symbolism: Potentially conflicting triad: the nurse (other healthcare professionals), the relatives and the patient.

Potential risks and Concerns

Questions:

How can diary use be utilised for the best benefit for patients?

What sort of support process should be in place?

How should this work?

Who should be involved?

What constitutes best investment of staff, time and resources in critical care aftercare provision?

Is there equity of process for all critical care patients?

Should the diary be seen as more than an add on to role, but part of nurses responsibilities to facilitate recovery?

Is it the most effective method or what are the alternatives?

Should there be follow-up processes that run in tandem with diary use and if so what form do patients feel this should take?

Appendix 4: ABHB Research Scrutiny and Research Risk Committee letters

GIG CYMRU NHS WALES | Bwrdd Iechyd Aneurin Bevan Health Board

Research & Development
Research Scrutiny Committee
Tel: 01633 656353
Email: Michael.Morgan@wales.nhs.uk

Ms Cheryl Phillips
Senior Lecturer
Faculty of Health, Sport and Science
University of Glamorgan
Pontypridd
CF37 1DL

Ref: RSC.24.11
11th May 2011

Dear Ms Phillips,

Patient diaries in critical care: an exploration of patient perceptions
Researcher: Cheryl Phillips
Reg: RD/958/11

The Research Scrutiny Committee reviewed the above study at their meeting held on the 4th May 2011.

The Committee agreed that the project was of great interest, very comprehensive and well written.

It was agreed the project be approved.

I wish you every success with this project.

Please note that no substantial changes or amendments can be made to the protocol without notifying the Trust Research & Development Office.

Kind regards

K. S. Hasell

pp Professor Sue Bale
Chairman
Research Scrutiny Committee

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Ms Cheryl Phillips
Senior Lecturer
Faculty of Health, Sport and Science
University of Glamorgan
Pontypridd
CF37 1DL

Ref: RRR.173.11.May
6th May 2011

Dear Ms Phillips,

Patient diaries in critical care: an exploration of patient perceptions
Researcher: Cheryl Phillips
Reg: RD/958/11

The Research Risk Review Committee reviewed the above project at their meeting held on the 4th May 2011.

The Committee agreed that overall the project did not appear to pose any risk to the Health Board and therefore your project has been approved. However, this approval is conditional on your project receiving a favourable opinion from the Research Ethical Committee.

It was noted that the forms have not been signed by the relevant persons. Also the patient information sheet does not confirm that the interview tapes will be destroyed at the end of the study. This needs to be inserted by the researcher into the patient information sheets.

Please forward a copy of this letter to the local ethics Committee. Once you have ethical approval, please forward a copy of your letter of approval to the Research and Development office at the above address.

If you require an Honorary Contract please contact the Health Board R&D Manager at the above address who will make arrangements to issue you with an honorary contract.

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NP20 4EZ
Tel: 01633 234234

May I take this opportunity to wish you success with your study and remind you that as Principal Investigator you are required to do the following:

a) Inform the Health Board R&D Office if any external funding is awarded for this study in the future
b) Inform the R&D Office of any substantial amendments/changes to your protocol
c) Maintain a record of the number of research participants are recruited into the study
d) Complete any questionnaires sent to you by the Health Board R&D Office regarding this project
e) Comply fully with the Research Governance Framework , and co-operate with any audit inspection of the project files
f) Undertake the project in accordance with ICH-GCP and the Trust's Guidelines on Good Research Practice
g) Adhere to the protocol as approved by the Local Research Ethics Committee
h) Ensure that your research complies with the Data Protection Act 1998
i) Report any serious adverse events to the R&D Office
j) If you do not commence your project within 12 months of approval being given by the Research Risk Review Committee, you must inform the R&D Office of the delay

Please note that all publications arising out of your research must include the following notice:

"This work was undertaken by Aneurin Bevan Health Board who received funding from the Welsh Ministers; the views expressed in the publication are those of the author/s and not necessarily those of the Welsh Minister."

Yours sincerely

A. S. Hawell

Professor Alex Anstey
Chairman
Research Risk Review Committee

Appendix 5: Favourable opinion SE Wales Research Ethics Committee

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR

Uned Cydlynu Caniatâd | PCU | Permissions Co-ordinating Unit

South East Wales Research Ethics Committee, Panel B
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone: 02920 3768 23
Website : www.nres.nhs.uk

20 September 2011

Miss Cheryl Phillips
MPhil/PhD student
University of Glamorgan
Room 7012
Faculty of Health, Sport & Science,
Lower Glyn Taff Campus
Pontypridd, Rhonnda Cynon Taff.
CF37 1DL

Dear Miss Phillips

Study title: **Patient diaries in critical care: an exploration of patient perceptions**
REC reference: **11/WA/0245**

Thank you for your letter of the 19 September 2011, responding to the Committee's request for further information on the above research, and for submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternate Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
- Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.
- Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.
- Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.
- For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.
- Sponsors are not required to notify the Committee of approvals from host organisations
- It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter	C Phillips	26 July 2011
Evidence of insurance or indemnity	UMAL	07 July 2011
Interview Schedules/Topic Guides	2	26 May 2011
Investigator CV	C Phillips	01 August 2011
Investigator CV	P Gill	29 July 2011
Letter from Sponsor	University of Glamorgan	08 April 2011
Letter of invitation to participant	2	13 June 2011
Other: Patient Demographic Sheet	2	24 May 2011
Other: Aneurin Bevan Health Board Research Risk Review Committee	A Anstey	06 May 2011
Participant Consent Form	3	19 September 2011
Participant Information Sheet	4	19 September 2011
Protocol	1	01 August 2011
REC application	IRAS 3.1	26 July 2011

Appendix 6: Participant Information sheet

Version 4 19/09/11

11/WA/0245

University of Glamorgan
Prifysgol Morgannwg
Faculty of Health, Sport and Science
Cyfadran Iechyd, Chwaraeon a Gwyddoniaeth

Participant Information Sheet

Study Title: Patient diaries in critical care: an exploration of patient perceptions

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. (If you wish please discuss participation with family, friends or carers). If anything is not clear or you require more information please feel free to contact me.

I appreciate you taking time to decide whether or not you wish to take part in the study.

What is the purpose of the study?

I am undertaking this research study as part of an MPhil/PhD. The purpose of the study is to explore patients' experience of critical care including perceptions of a diary written on their behalf by nurses during their admission to critical care. (You may have heard critical care described in different terms such as; intensive care, ITU or HDU, but they mean the same thing).

Why have I been invited?

The critical care unit that you were admitted to uses patient diaries and the research study aims to explore your perceptions. I am interested in your views regardless of whether you have decided to collect your diary or not.

Do I have to take part?

It is up to you to decide if you wish to take part in the study. I will describe the study and go through the information sheet which you have received. I will answer any questions you may have about the study. If you wish to take part in the study please

read, sign the consent form and return it to me in the prepaid envelop provided. You are free to withdraw from the study at any time, without giving a reason and without any detriment to you.

What will happen to me if I take part?

- The research study will require you to attend an initial interview and two further interviews over a 12 month period, which will be audio-taped and then transcribed and anonymised direct quotes will be used with your permission. The information collected will be anonymous and your confidentiality will be maintained at all times.

- The interviews may last up to 60 minutes for the initial one and less for subsequent interviews. I aim not to keep you longer than necessary as I appreciate your time is valuable.

- With your permission I would like to access a copy of your diary which will only be used in conjunction with the information provided by you in the interviews, but this is not essential. I would also like to collect anonymous information about the reason for admission, length of time ventilated and sedated, severity of illness and dates of admission and discharge as part of the study.

Expenses and payments

Provision will be made to reimburse you should travel expenses and parking fees be incurred.

What will I have to do?

You would be asked to attend three agreed scheduled interviews over a period of a year and you can choose whether you want me to meet with you in your own home or at the University of Glamorgan campus if you prefer.

What are the possible disadvantages and risks of taking part?

I fully appreciate the contribution you would be making to the study in terms of giving your time and sharing your experience and views, if you decide to take part.

The interview may result in you recollecting unpleasant memories or feelings. It may be necessary for me to pause or stop the interview if you are distressed. If you wish you can pause or stop the interview at any time as your well-being is paramount.

I have included support service contact details that you may find useful at the end of this information.

If during the interviews you raise any issues of concern e.g. a suggestion of malpractice or regarding your own well-being then I will discuss this with you at the time it is raised and explain the course of action to be taken as a result with you. It will

be my responsibility to ensure any issues of concern are referred to the appropriate healthcare professionals and that your well-being is maintained.

What are the possible benefits of taking part?

I cannot promise that the study will help you, although some people find it helpful to talk through their experiences. However, the information you provide will help me to explore patient views which will inform future critical care practice.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions:

Cheryl Phillips Tel: 01443 483818

(If I am not in the office please leave a voicemail and contact number, if you wish, and I will return your call as soon as I possibly can).

If you are concerned about the researcher or the manner in which the research has been carried out and wish to complain formally you can do this by contacting:

Karen Roberts (Research Officer) Tel: 01443 483158

Will my taking part in the study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the hospital/surgery/university will have your name and address removed so that you cannot be recognised.

Your confidentiality will be safeguarded at all times during and after the study. All data will be anonymous and the researcher will ensure that your data is stored securely and that data is protected appropriately when handling, processing and storing your data, which will be stored on the researcher's password protected University of Glamorgan computer.

Only the researcher will have access to the data collected which will have a code known only to the researcher. The interviews will be audio-taped and transcribed. Audio-tapes will be destroyed at the end of the study. The transcripts will be discussed with the researchers' supervisor, but your anonymity will be maintained. Hard paper/taped data will be stored in a locked cabinet, within locked office, accessed only by researcher. Your data will be retained for 5 years at which point it will be disposed of securely.

What will happen if I don't carry on with the study?

If you wish to withdraw I can either destroy your interview audio-tapes and data or with your permission I could use the data collected up until your withdrawal from the study.

What will happen to the results of the research study?

The results of the study will be sent to you as a hard copy for your perusal and any comments welcomed. The study will form the basis for some reports and publications but you will not be identified; only anonymous data will be included.

Who is organising or sponsoring the research?

The researcher is an MPhil/PhD student at the University of Glamorgan and the research is funded by a grant from Research Capacity Building Collaboration (RCBC) Wales.

Further information and contact details:

If you have any queries about this research please do not hesitate to contact the researcher:

Cheryl Phillips Tel: 01443 483818

(If I am not in the office please leave a voicemail and contact number, if you wish, and I will return your call as soon as I possibly can).

Alternatively you can E mail me on: cphilli1@glam.ac.uk

Information Sheet based on: COREC/NHS National Patient Safety Agency. *Information Sheets and Consent Forms – Guidance for Researcher and Reviewers'* Version 3.0 Dec 2006.
Link to IRAS website - IRAS

Support Services

You can make an appointment with your GP to discuss any issues that are concerning you and to gain advice.

These are some support services that may be of use in some circumstances:

CARELINE Helpline 0870 241 3337

Careline provides confidential telephone counselling for children, young people and adults. We offer a unique service in that we can provide instant telephone counselling to any individual on any issue.

The calls we receive include family, marital and relationship problems, rape and sexual assault, child abuse, bullying, exam worries, eating disorders, HIV/AIDS and sexual health, bereavement, drug and alcohol addictions, homelessness, disability, ethnic issues, stress, depression, loneliness, anxieties and phobias.

Careline also provides a face-to-face counselling service to adults who might otherwise find counselling beyond their resources.

At Careline we have an extensive referral system covering the whole country and can offer to refer callers to a specific agency or support group in their area if they should wish.

SUPPORT & SELF HELP IN SURVIVING TRAUMA

ASSIST Helpline: 01788 560800

Assist provides Assistance Support & Self help In Surviving Trauma

Email:assist@traumatic-stress.freeserve.co.uk

Assist is an organisation dedicated to offering support, understanding and friendship to individuals and families affected by Trauma.

Information on Post Traumatic Stress Disorder and general issues related to trauma.

www.uktrauma.org.uk

Appendix 7: Informed consent form

Version 3 19/09/11
11/WA/0245

University of Glamorgan
Prifysgol Morgannwg
Faculty of Health, Sport and Science
Cyfadran Iechyd, Chwaraeon a Gwyddoniaeth

Informed Consent Form

Study Title: Patient diaries in critical care: an exploration of patient perceptions

Please tick to confirm

I agree to take part in the above Faculty of Health, Sports and Science (University of Glamorgan) research study. ☐

I have had the research study explained to me, and I have read the Participant Information Sheet (version4 dated: 19/09/11). ☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without detriment to me. ☐

I understand that agreeing to take part means that I am willing to:

- be interviewed by the researcher ☐
- allow the interview to be audio-taped and transcribed ☐
- Allow the researcher to use anonymised direct quotes ☐

- make myself available for a total of three interviews over 12 months ☐

Optional request:

- Allow the diary project team (Critical Care Nurse) to collect anonymous demographic data held in my medical notes on behalf of the researcher. ☐
- Allow the researcher to use data collected up until your withdrawal from the study should you decide to opt out at any stage. ☐

Data Protection

Please tick to confirm

This information will be held and processed for the following purpose(s): ☐

- To inform the research study and further research identified as a result.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. ☐

I agree to Cheryl Phillips (University of Glamorgan) recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act (1998). ☐

Name: .....(please print)

Signature: .....Date: .....

Name: .....(please print)

Signature.....Date:.....

Address:.....

Appendix 8: Transfer viva report

Transfer from MPhil to PhD, Faculty of Health, Sport and Science

Name of Candidate: Cheryl Phillips

Title of Thesis: Patient Diaries in Critical Care: An Exploration of Patient Perceptions

Reviewer: Professor Neil Frude

Date: 21/12/12

General comments

Introduction/Literature Review: Cheryl has made very good progress in conceptualizing the relevant clinical and ethical issues and is well aware of previous research in this area. Following her own Grounded Theory analysis she will be in a good position to examine relevant theoretical aspects (including coping with trauma, the use of narratives, etc.) and this will enable her to put her own work into a broader theoretical context.

Aims and Objectives: These are very clear. They make a good argument for this being a clinically useful and timely study.

Methodology: The methodology chosen – Glaserian Grounded Theory – is eminently suitable to the project. Cheryl has undertaken appropriate training and is well versed in this approach.

Progress: Cheryl is making very good progress. She has set herself a demanding timetable but is working to this very well. She has shown extreme diligence and application. Her ability to explain and converse about the project demonstrated that she is thoroughly on top of all aspects of her work. I can see no specific hurdles or barriers that might prevent this project leading to an excellent PhD thesis delivered on time.

Proposed Future Work: Cheryl set out her project plans in 2010 and has followed these without any need for modification. Her analysis so far does not suggest any need for change, and so her plan – which I fully endorse – is that she will carry on collecting data to allow her to expand her emerging grounded theory. When her analysis of her own data is complete, she will then be in a good position to consider her findings in the light of existing relevant theories. She will also be able to work on the implications of her work for clinical practice and service delivery.

Suggested dates for transfer viva: This was held on the 20/12/12

Cheryl performed very well, answering all queries with insight and thoroughness demonstrating that she is fully on top of the work she is doing. There was absolutely nothing to suggest that she will not be able to produce a creditable and successful thesis within the timetable that has been set.

Recommendations (please see below for guidance and please provide further information and/or recommendations – e.g., suggestions for future work - if appropriate):

The transfer process **should have one** of the following outcomes:

- Proceed to PhD
- Not to proceed to PhD and to submit for MPhil
- Make amendments to the report and resubmit for further assessment

My recommendation is very clear – that Cheryl be permitted to proceed to PhD

Professor Neil Frude – 21/12/12

Appendix 9: Qualitative versus Quantitative Research Methods

QUANTITATIVE	QUALITATIVE
Tests hypotheses	Generates hypotheses
Aims to explain, predict or control phenomena through focused numerical data collection	Aims to gain insight and understanding of phenomena in an attempt to explain it
Generally deductive, objective and outcome orientated	Generally inductive, subjective, holistic and process orientated
Studies range of people in a sampling of people in the population	Studies range of ideas in a sampling approach that represents ideas or concepts
Literature review is extensive, but does not significantly affect the study	Limited literature review that does not significantly affect the study
What, how much and how many?	Why & what does it mean?
Research setting is controlled as much as possible	Research setting is as naturalistic as possible
Sample is random with the intention of recruiting a large number of participants in order to generalise result to the population	Sample is purposive with the intention of recruiting a small number of participants to gain an in-depth understanding
Captures numerical data about frequency, severity and associations from a large number of participants	Captures rich, contextual & detailed data from a small number of participants
Data analysis: raw data are numbers and performed at the end of the study	Data analysis: raw data are words and analysis is ongoing and involves synthesis
Conclusive: tries to quantify the issue under study	Exploratory: tries to define a problem when we do not know what to expect
Study measurement is standardised, numerical and data analysis is conducted at the end of data collection	Study measurement is non-standardised and data is narrative based and data analysis is on-going throughout the study
Randomised control trials (RCTs) Descriptive Correlational Causal-comparative Experimental	Hermeneutic & phenomenological research Naturalistic inquiry Ethnomethodology Ethnography Qualitative case study Participatory action research Grounded Theory
Surveys Audits Questionnaires Clinical Trials	Focus groups In-depth interviews Unstructured interviews Observation
(Kvale & Brinkmann, 2009, Hewitt-Taylor, 2011, Polit & Beck, 2012, Silverman, 2013, Hughes, 2014)	

Limitations

QUANTITATIVE	QUALITATIVE
Human experience is complex and it is difficult to rule out or control all variables	Validity and reliability are seen as questionable because of the subjective nature of the data and interpretation.
People respond differently even in the same circumstances and this is difficult to quantify	It is argued that generalisations cannot be made
The method tends to exclude ideals of freedom, choice and morality	Data collection and analysis can take a long time

It cannot take account of people's unique ability to interpret their experience and to find meaning upon which they act	The researcher role in qualitative studies can influence participants
	Anonymity and confidentiality need careful consideration when relating to findings
(Silverman, 2013, Hughes, 2014)	

Strengths

QUANTITATIVE	QUALITATIVE
Precision: quantitative and reliable measurement	Researcher role can lead to an insider view of the area under study, highlighting issues that otherwise might have been missed by the scientific quantitative approach
Control: sampling and design	Qualitative descriptions offer insight into complex relationships, causes, effects and responses
Ability to present causal statements: controlled experiments	The narrative descriptive style can make the research more applicable and accessible to clinical staff; thereby contributing to their knowledge and informing their clinical practice.
Statistical analysis can be sophisticated	Qualitative research adds a human perspective that quantitative research has to spurn in favour of factual, numerical results.
Replicable findings	It is not necessarily able to be replicated and is more often subjective in nature.
(Silverman, 2013, Hughes, 2014)	

Method of data collection	Consideration
Focus Groups Deal with small numbers 6-10 in one swoop Capture a variety of views and opinions Quick results Low cost Discussion based responses	The research did think about using focus groups, but ruled it out because she felt gathering the participants in such a way could lead to contamination or constraining of individual perceptions. There would need to be two people involved: one to facilitate and another to moderate and take field notes. There is the risk that one participant could dominate discussion at the expense of the others. Participants may be less likely to share their true thoughts in such an open arena. Recording and accurately transcribing discussion can be troublesome with multiple conversations/ overlaps going on. It is for these reasons the researcher ruled out focus groups
Questionnaires & surveys Quick data collection tools. Require piloting to ensure interpretation of questions works before finalising the product for use.	But with a requirement for a certain response rate to meet a significant enough number of respondents to be representative of the group being studied. Also the tool is self-completed and it can be subjective

Relies on respondents to complete and return Can be postal or electronic.	because there is no option for researcher-respondent clarification or exploration beyond the answer provided. Even using an open ended question at the end seems to have potential for only a limited response. It is impersonal and the area of research is quite an emotive topic so the researcher also ruled this option out.
Interviews: in-depth, structured or unstructured Face to face researcher-participant	The researcher chose to select Serial Qualitative Interviews (SQI) for the data collection as that would allow exploration of responses to allow calcification and representation of participant view, perceptions and beliefs if done well. If done over time it also enables a researcher- participant relationship based on trust to develop and potentially lead to further disclosure than might occur in a one off interview. Provides opportunity to gain rich descriptions that facilitate data analysis
(Kvale & Brinkmann, 2009, Hewitt-Taylor, 2011, Polit & Beck, 2012)	

Appendix10: Current construction, types of diary and roles

Since this study began there has been an evolution in types and structure of critical care diary. Arguably this adds to the complexity of determining what form of diary is most appropriate and useful to patients:

TYPE & CONSTRUCT	SOURCES
Prospective diaries written as events unfurl	Bäckman & Walther, 2001, Combe, 2005
Retrospective summary of events at outset of diary to enable diary to outline whole picture of critical illness journey	Jones, 2009a, Gjengedal *et al*., 2010
Possible lay discharge summary to aid in understanding events	Bench *et al.,* 2012
Photo-diary using both written entries and photographs	Bäckman & Walther, 2001, Jones, 2009a, Jones *et al*., 2010, Jones *et al.*, 2012
Nurse composed diaries	Gjengedal *et al.,* 2010
HCPs & family diaries	Jones *et al.,* 2012, Garrouste-Orgeas *et al.,* 2012
Family constructed diaries	Wellington ICU, New Zealand
Visual diarising by patient during recovery	Ewens *et al.*, 2014a

Current descriptions of the role of patient diaries in critical care

Memory gap: (Jones, 2009a, Gjengedal *et al*., 2010, Egerod *et al*., 2011a)

Giving back time: (Bäckman, 2011)

Help relatives as well as patient: (Jones *et al.,* 2012, Garrouste-Orgeas *et al*., 2012)

Help patient construct autobiographical story of critical illness during recovery (Ewens *et al.*, 2014a).

Nurses and act of caring through diary writing (Gjengedal *et al*., 2010)

Appendix 11: CURRICULUM VITAE

Name:	
Cheryl Phillips	
Present appointment:	
Senior Lecturer Adult Nursing/Critical Care, Faculty of Life Science & Education, University of South Wales.	
Address:	
University of South Wales (Formerly University of Glamorgan), Faculty of Life Science & Education (FLSE) Room AB017, Lower Glyn Taf Campus, Pontypridd. Rhondda Cynon Taff. CF37 1DL	
Telephone number:	**Email address:**
01443 483818	cherylphillips@southwales.ac.uk
Qualifications:	
2005 PGCE University of Glamorgan 2003 MSc Nursing UWCM 1995 Research module & 1994 ENB 100 & 998 (Diploma in critical care) 1992 Research ENB 870	
Professional registration:	
NMC Pin: 86Y3011E registered since January 1990.	
Previous and other appointments:	
Senior Lecturer post since 2005 to present	
RCBC Wales Fellowship & Community of Scholars	
I was awarded an RCBC Wales Fellowship which is an externally funded research grant, enabling me to have allocated time to complete my PhD studies part time over 5 years. My PhD is titled Patient diaries in critical care: an exploration of patient perceptions. These are diaries written by nurses on behalf of patients while they are ventilated and sedated in critical care (commenced September 2010). I attend Bimonthly Community of Scholars meetings with other RCBC Wales Fellows and share PhD research experiences which provides a network of people in similar situations doing PhDs and this is a useful resource. Sessions covered: • 27th June 2013 RCBC COS Academi Wales leadership Summer School • 6th March 2013 RCBC COS Strategy & influence: the working of the public sector.	

- 23rd April 2013RCBC COS Methodology: cutting edge ideas & developments
- 21st November 2012 RCBC COS PROFESSIONAL DEVELOPMENT FOR FUTURE CLINICAL LEADERS:The Quad of Aims, the MTQ-48 and Building a 'new' Community of Scholars.
- 24th & 25th September 2012 RCBC Away days Co-production
- 12th July 2012 UHW Cardiff University, Dragons Den with Welsh Government & Health Board representatives as Dragons.
- 9th -10th May 2012 Bangor University, Q+A session on career development post-RCBC
- 8th March 2012, Swansea University, Research Presentations update on our research.
- 12th January 2012, University of Glamorgan, Story Telling, Storyworks.
- 2nd November 2011, Future's Inn, Welsh Government & Political Awareness training and visit to Assembly.
- 15th -16th September 2011 Parc Hotel, Cardiff, RCBC Away Days, Adding Value to your Studies
- 7th July 2012, UWIC, Methodological Issues with Survey Data and Writing Skills
- 5th May 2011, Glyndwr University, VIVAS.
- 3rd March 2011, Swansea University, Experimental analysis and statistical methods
- 6th January 2011, Cardiff University, Peer Support
- 4th November 2010, University of Glamorgan, Atrium, Media Training.
- 23rd -24th September 2010, Away Days and Showcase Conference, Swansea Towers Hotel, Media Training, Research and Clinical Practice.

Research training:

- Masterclass: Grounded Theory, Bournemouth University 18th & 19th June 2012 (Professor Immy Holloway & Dr Liz Norton).
- Good Clinical Practice Training 28/03/11 Cardiff University
- NVIVO training 02/03/11 University of Glamorgan
- Qualitative Interviewer Training workshop 23/11/10 University of Glamorgan

Relevant publications:

- Higginson R., Jones B. & Phillips C. (2009) CELT project: The use of clinical simulation and human patient mannequins in pre-registration nurse education.
- Lipp A., Phillips C., Harris P. & Dowie I. Systematic Review No: 078 Cyanoacrylate based microbial sealants for skin preparation prior to surgery. Published in the Cochrane Library, (Issue 10, 2010, publication date 6 October 2010).
- Lipp A., Phillips C., Harris P. & Dowie I. (2011) Cyanoacrylate as a microbial sealant: examining the evidence. Journal of Perioperative Practice 21(3) 88-92
- Dowie I. & Phillips C. (2011) Supporting the lecturer to deliver simulation of clinical practice. *Nursing Standard.* 25(49) 35-40
- Phillips C. (2011) Patient diaries in critical care: an exploration of the literature. *Nursing Standard*. 26(11)35-43.
- Wood C, Phillips C. Cyanoacrylate microbial sealants for skin preparation prior to surgery. *Cochrane Database of Systematic Reviews* 2016, Issue 5. Art. No.: CD008062. DOI: 10.1002/14651858.CD008062.pub4.

Conferences:

- Policy Forum for Wales (2014) Next steps for unscheduled care in Wales: reform of ambulance, emergency and critical care services. Panel member and oral presentation on my research Tuesday 14th October. Raddison Blu, Cardiff.
- ABUHB Research Conference (2014) Oral presentation. Newport..
- BACCN Conference (2013) Oral presentation. Southport.

• Chief Nursing Officer for Wales (2011) Showcase Conference. SWALEC Stadium, Cardiff: Establishing patient views of diaries: altering the boundaries of critical care. Cheryl Phillips, Amanda Hale, Tracey Rich & Louise Parfitt.. Awarded second prize for poster presentation.
External roles
British Association of Critical Care Nurses (BACCN) National Board member since September 2014.